

# Toward empowerment : screening prolonged grief disorder in the first six months of bereavement

She, Wan Jou

Published: 15/02/2018

## *Document Version*

Publisher's PDF, also known as Version of Record (includes final page, issue and volume numbers)

### **Please check the document version of this publication:**

- A submitted manuscript is the author's version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

## *Citation for published version (APA):*

She, W. J. (2018). Toward empowerment : screening prolonged grief disorder in the first six months of bereavement Eindhoven: Technische Universiteit Eindhoven

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

# TOWARD EMPOWERMENT

Wan Jou (Lavender) She



Screening Prolonged Grief Disorder in  
the First Six Months of Bereavement

# TOWARD EMPOWERMENT

Screening Prolonged Grief Disorder in the First  
Six Months of Bereavement



Wan Jou (Lavender) She

A catalogue record is available from the Eindhoven University of Technology Library

ISBN: 978-90-386-4450-9

She, Wan Jou (Lavender)

Toward Empowerment Screening Prolonged Grief Disorder in the First Six Months of Bereavement

Proefontwerp Technische Universiteit Eindhoven

Designed Intelligence Research Group / Faculty of Industrial Design

Keywords: Bereavement, Prolonged Grief Disorder, Self-monitoring system, Internet-based Bereavement Support, Resilience, Design for Empowerment.

Nur: 964

Interior layout with Adobe InDesign

Cover design: Wan Jou (Lavender) She

Copyright © Wan Jou (Lavender) She 2018. All rights reserved.

Printed by: Dissemination || [www.proefschriftmaken.nl](http://www.proefschriftmaken.nl)

# TOWARD EMPOWERMENT

Screening Prolonged Grief Disorder in the First Six Months of Bereavement

PROEFONTWERP

ter verkrijging van de graad van doctor aan de Technische Universiteit Eindhoven, op gezag van de rector magnificus prof.dr.ir. F.P.T. Baaijens, voor een commissie aangewezen door het College voor Promoties, in het openbaar te verdedigen op donderdag 15 Februari 2018 om 16:00 uur

door

Wan Jou (Lavender) She

geboren te Kaohsiung City, Taiwan

## Acknowledgement

De documentatie van het proefontwerp is goedgekeurd door de promotoren en de samenstelling van de promotiecommissie is als volgt:

voorzitter:	prof.dr.ir. A.C. Brombacher
1e promotor:	prof.dr. G.W.M. Rauterberg
2e promotor:	prof.dr. M.J. Verkerk
copromotor(en):	dr. J. Hu PDEng MEng
leden:	prof.dr. R.A. Neimeyer (The University of Memphis) prof.dr. A. Català (Universitat politècnica de Catalunya) prof.dr. P.A. Boelen (Universiteit Utrecht)
adviseur(s):	prof.dr.ir. L.M.G. Feijs

Het onderzoek of ontwerp dat in dit proefontwerp wordt beschreven is uitgevoerd in overeenstemming met de TU/e Gedragscode Wetenschapsbeoefening.

Japanese tea ceremony describes the spirit of treasuring each gathering with others as “Ichi-go ichi-e” (一期一会, “one time one meeting” or “one chance in a lifetime”). It reminds us that every session in our life is once-in-a-lifetime. People grow older, seasons shift, environment changes, and life paths diverge. Even if the same group of people gathers again, the meeting is essentially a different one with a different mood, changed ambiance, more life experiences and older age. The completion of the thesis has marked an end to my PhD Ichi-go ichi-e, and I want to express my gratitude to all of you that take part in this unique session. Thank you for sharing your unrepeatable moments with me and leaving your mark in my Ichi-go ichi-e.

My sincerest thanks goes to my parents (YUKUN SHE and YENMEI LIN) and brother (CHENYU SHE) who have offered me many years of unconditional love and mental shelter. It allows me to explore and march forward fearlessly. Your warm words and emotional support have made the distance between the Netherlands and Taiwan short and have accompanied me in the most challenging moments during the PhD journey. I wish to share the glory with all of you.

I also wish to thank Taiwanese government for the grant that allows the project to happen, and hope the findings of my project can contribute to the aging society in my home country.

There are five heroes (heroines) along this pilgrimage the deserve my heartfelt thanks.

Matthias Rauterberg, my diligent brainiac, but slightly socially clumsy, supervisor who has profoundly shaped my characteristic and scientific spirit. Thank you for spending a substantial amount of time in many meaningful/scientific Ichi-go ichi-e(s) and even more heuristic chit-chat sessions. You are the supervisor that answers student’s phone on Christmas Eve, knocks on the studio door to ask if she needs more time discussing, responds emails even though automatic holiday response is active, and, most importantly, listens to my wish of designing a therapy site and apologetically tells me that it is IMPOSSIBLE (wait, what?!). Memories are bittersweet, and these moments render my PhD pilgrimage unforgettable and unrepeatable. You are the very best supervisor for this project and a student like me. I believe what I learned from you will continue to enlighten me on my future endeavor.

Priscilla Chueng-Nainby, my spiritual mentor and lifelong friend. You are the critical role that leads me towards becoming a PhD. I am inspired and even rescued by your passion

and wisdom every now and then. You are the witness of my PhD pilgrimage and the first one who wholeheartedly trusts that I have a “PhD quality.” I have learned and grown a lot through frequent conversations with you as you generously accommodate and healed my insecurity and trauma. Words are not sufficient to express my thanks to you, and I am fortunate to have your participation in many critical moments of my life.

Panote Siriaraya, my code savvy **ともだち** (friend) and human intelligence resource (in comparison to artificial intelligence). You are my role model as an early career researcher and a versatile computer scientist. Seeing you bounce back from challenging life conditions have recalibrated my standard of living a meaningful life and still contributing to the society. I want to thank you for the immediate coding support, emotional comfort, Japanese tutoring and scientific knowledge sharing.

Laurie Burke and Robert Neimeyer, my external supervisors and the best gift in my PhD research. The GIFT study was made possible because of a review paper written by you. You are the critical roles that connect me with the very field that I wish to contribute and your warm-hearted words in the emails have always motivated me. I could never picture me working with bereavement research gurus until I attempted and got consent to collaborate with. I wish to thank you for the initial long emails that solidify my confidence in conducting the GIFT study and the patient guidance that facilitates a fruitful finding.

Besides the legendary heroes. There are more important people in my life that make this pilgrimage less lonely.

Best appreciation to Sabine Smits, who is the godlike secretary that always makes our wishes come true. Thanks for always doing much more than what a secretary is conventionally responsible for. If it were not you, I would not be able to arrange the defense so smoothly.

I wish to thank my grandparents (Zhi-He Sher and Jin-Jiu Sher Su from father side) who have directly inspired this project and my grandparents (Xiu-Zhi Huang and Chun-Zhong Ling from mother side) who have remained healthy, so I still have a chance to enjoy quality time with them after my PhD.

I also want to thank Evan Ming-Hsueh Wu, who is the one that tolerates my ill-temper and answers all the aggressive questions. You are the best partner, friend, soulmate and life experience mentor.

My supervisory team members, Jun Hu, and Maarten Verkerk thank you for your immediate attention that helps me to overcome the barriers in my thesis. Jun, you are culturally close to me and can offer many nuanced tips while I am struggling. Maarten, you have been a brilliant last

touch in my Ph.D. project. It was a very pleasant experience collaborating with you.

I also want to thank the committee members who kindly offer the brilliant last touch to the thesis. Robert A. Neimeyer, Andreu Català, Paul A. Boelen and Loe Feijs, thank you for the professional and valuable comments.

My colleagues from the Memorial Sloan Kettering Cancer Center and Weill Cornell Medicine who generously provided their questionnaires to support my study. Thank you, Wendy Lichtenthal, Kailey Roberts, and Holly Prigerson.

Many thanks also go to my colleagues at Eindhoven University of Technology. My best roomies Xinwei (and semi-roomie Martijn ten Bhömer) and Kadian. The time we shared in the same studio and the gossip we exchanged about our PhD experiences are my timeless treasures. Lady’s night friends, Kyra, Begum and Giulia. Thank you for the sweet talks and encouraging. My delivery food friend and bester sister in the faculty, Xu Lin. Thank you for feeding me, LOL! Yu Zhang, thank you for frequently listening to my complains and inviting me for several walks in the campus. The technical forerunner, Mart Wetzel. Thank you for maintaining the server and providing back-end support for my website. Rong-Hao, who has been like a reliable brother and brought a lot of warmth from Taiwan. I have to thank the emotional support and quality time shared with Bin Yu, Dirk, Feng Yuan, Eric the fellow gamer (Ha), Matthias Funk, Mark, Jing Ya, Monru, Nan Yang, Ning Zhang, Peggy Peng, Yudan Ma and many more colleagues.

Besides the Eindhoven colleagues, I am also deeply in debt to Eunice and Gotham who brought cheers to my life during my difficult times and who were always the first ones to turn to when I need immediate support.

I also want to address my thanks to my Delft fellows Jie, HaoZheng, Stella, Chen Hao, all members from Delft Institute of Positive Design (The Happiness Group!), Fenne, DongJuan, Wei Liu, Aadjan and many more friends that made my journey in the Netherlands fruitful.

As my pilgrimage reaches the shrine, my faith grows stronger. I believe the best time is the time we live with no regret and part with full appreciation. I will look forward to more Ichi-go ichi-e. Love all of you.

Wan Jou (Lavender) She

Eindhoven, January 10, 2018.

# Summary

## Background:

Previous bereavement-related literature indicated that around one out of ten (9.8%) bereaved individuals could suffer from a more severe and protracted grief, entitled Persistent Complex Bereavement Disorder (PCBD) in the DSM-V, or Prolonged Grief Disorder (PGD) in ICD-11. To precisely differentiate the prolonged grievers from the normal grievers, a minimum six months is required, and to offer psychotherapeutic intervention to normal grievers indifferently could instead hamper their natural coping mechanism. The fact conflicts with the fact that the severely maladapted grievers might need psychotherapeutic support in a more timely manner, and might even benefit from earlier intervention. This dilemma indicates that there is a need for a screening method in the first six months of bereavement.

## Objective:

Based on the above discussion, the objective of the thesis is to develop a screening method for prolonged grief disorder that is empirically tested and can be embedded in an internet-based application.

## Approach:

A mixed approach is adopted to fulfil the research objective. The research is divided into three phases with Phase 1 concentrating on exploring the design opportunities, Phase 2 developing an internet-based data gathering system to collect questionnaires data for building predictive models, and Phase 3 building the regression model and implementing the model into the internet-based screening app.

## Method:

Phase 1 implements a qualitative study to explore the design opportunities of technology in supporting the bereaved. In Phase 2 we designed a data gathering system that targets on gathering data that measure bereavement risk factors and insights into user experiences on using self-screening application in the bereavement context. In Phase 3 three models were built and one selected to be implemented in the final deliverable, an internet-based screening application.

## Results:

From the qualitative study in Phase 1, building an internet-based screening method that can contribute to empowering the decision-making in bereavement was chosen to be further conceptualized into an app. In Phase 2, an internet-based data gathering system entitled Grief Inquiries Following Tragedy (GIFT) was proposed as a preliminary prototype and a research instrument for gathering data to empirically validate the screening method. The five protocol analysis sessions exhibited insights of improvement regarding the functionality, language and user interface on GIFT. These insights were implemented before deploying GIFT for a larger scale online data gathering. With the data gathered from 611 participants, three predictive models were fitted and compared based on cross-validating their predictability in successfully identifying prolonged grievers in Phase 3. Model 2 that was fitted based on socio-demographic factors and PGD risk factors demonstrated the highest predictability (successfully identify 40% of prolonged grievers on the unselected cases) among the three, and was selected for further implementation on the final deliverable app, Empowered to Grieve (EtG).

## Conclusion:

The predictive formula based on Model 2 is implemented in the predictive algorithm of EtG (accessible through the following URL: <https://www.designempowerment.com>). The major screening function of EtG is to calculate the predicted probability of developing PGD and provide feedback based on the predicted outcome to the users. It is expected that the bereaved users could evaluate their risk of developing PGD within the first six months of bereavement, and this interaction with EtG would empower their decision-making in whether they will benefit from clinical interventions.



# Contents

<b>ACKNOWLEDGEMENT</b>	<b>VII</b>
<b>SUMMARY</b>	<b>X</b>
<b>CHAPTER 1 INTRODUCTION</b>	<b>2</b>
1.1 Problem Definition and Research Opportunities . . . . .	3
1.1.1 The context of the research . . . . .	3
1.1.2 Problem definition . . . . .	4
1.1.3 Research opportunities. . . . .	5
1.2 Research Questions. . . . .	6
1.3 Research Objectives . . . . .	6
1.4 Thesis Organization . . . . .	7
1.4.1 Publications and prior work. . . . .	7
<b>CHAPTER 2 LITERATURE REVIEW</b>	<b>9</b>
2.1 An Overview of the Bereavement Theories . . . . .	9
2.1.1 The grief work hypothesis and the traditional approach of understanding grief	9
2.1.2 The recent development on bereavement models and bereavement interven-	12
tions . . . . .	12
2.2 The Maladaptive Reaction in Bereavement . . . . .	14
2.2.1 Diagnosis of PGD. . . . .	15
2.2.2 Epidemiology . . . . .	15
2.2.3 Further threads in PGD treatment research . . . . .	16
<b>CHAPTER 3 IDENTIFY THE ACTIVITY-BASED DESIGN OPPOR-</b>	
<b>TUNITIES IN THE BEREAVEMENT CONTEXT</b>	<b>19</b>
3.1 Introduction. . . . .	19

3.2 Defining Activity . . . . .	20
3.2.1 Activities in the bereavement literature . . . . .	20
3.2.2 Coping, Intentional Activity and Well-being . . . . .	22
3.3 Activity and Interaction Design. . . . .	23
3.3.1 Activity Theory and the Activity-Centered Design in HCI. . . . .	23
3.3.2 The hierarchical structure of activity, action and operation . . . . .	24
3.4 Study Design and Analysis . . . . .	24
3.4.2 Types of loss experience reported. . . . .	25
3.4.3 First phase of study-sensitizing and preparing the participants . . . . .	26
3.4.4 Second phase of study-interview . . . . .	26
3.4.5 Analysis . . . . .	27
3.5 Result . . . . .	27
3.5.1 Meaningful activities . . . . .	29
3.5.2 Positive outcomes (PO) . . . . .	36
3.5.2 External support (ES) . . . . .	38
3.6 Discussion. . . . .	39
3.6.1 Comparing with preceding studies . . . . .	39
3.6.2 The role technology plays in the coping process . . . . .	40
3.7 Limitations and Conclusion. . . . .	42
3.7.1 Limitations . . . . .	42
3.7.2 Conclusion . . . . .	43

<b>CHAPTER 4 THE DEVELOPMENT OF A MONITORING AND</b>	
<b>FEEDBACK SYSTEM FOR PREDICTING POOR ADJUSTMENT TO</b>	
<b>GRIEF</b>	<b>45</b>
4.1 Introduction. . . . .	45
4.2 Context of Usage-Bereavement . . . . .	46
4.3 Two Approaches to Predict PGD symptoms in Early Phase . . . . .	47
4.4 Method . . . . .	48
4.4.1 The design and conceptualization of two prototypes of PGD screening methods	48
4.4.2 External experts from the bereavement and psychotherapy field . . . . .	49

4.4.3 My Grief Journal . . . . .	49
4.4.4 Grief Inquiries Following Tragedy (GIFT) . . . . .	50
4.4.5 The evaluation of both apps and the pilot test of GIFT . . . . .	59
4.5 Result . . . . .	59
4.6 Discussion . . . . .	60
4.6.1 Participants' experiences of support seeking on the Internet . . . . .	63
4.6.2 The benefits and challenges of a grief self-monitoring app . . . . .	66
4.6.3 Language use in the bereavement context . . . . .	70
4.6.4 Navigation design of the app . . . . .	76
4.6.5 Functionality of the app . . . . .	79
4.7 Limitations . . . . .	80
4.8 Conclusion . . . . .	80

## CHAPTER 5 FITTING AND EVALUATING THREE REGRESSION MODELS TO SCREEN PGD WITH GIFT 83

5.1 Implementing GIFT as an Instrument for Study Data Collection . . . . .	84
5.1.1 The language use of GIFT . . . . .	85
5.1.2 The functionality of GIFT . . . . .	95
5.1.3 The Navigation of GIFT . . . . .	103
5.1.4 Preparing to deploy GIFT on the Internet . . . . .	106
5.2 Studying Method . . . . .	108
5.2.1 Ethical consideration . . . . .	108
5.2.2 Deployment of GIFT DG and data collection . . . . .	108
5.2.3 Data extraction . . . . .	108
5.2.4 Analysis . . . . .	109
5.3 Results . . . . .	111
5.3.1 The Socio-demographic data of study participants and the deceased . . . . .	111
5.3.2 Model 1 with only background factors . . . . .	116
5.3.3 Model 2 with background factors and bereavement risk factors . . . . .	119
5.3.4 Model 3 with background factors, bereavement risk factors and bereavement outcome factors . . . . .	124

5.4 Discussion of the Quantitative Findings . . . . .	129
5.4.1 The imperative need for a PGD risk factors measuring instrument . . . . .	130
5.4.2 Not many socio-demographic factors are effective predictors . . . . .	130
5.4.3 Model 1 fitted with the background factors being the poorest performant model . . . . .	131
5.4.4 Model 2 fitted with background factors and bereavement risk factors being the most performant model . . . . .	131
5.4.5 Model 3 fitted with most of the variables yet yields the opposite effect in performance . . . . .	132
5.4.6 Comparison of the three models . . . . .	133
5.4.7 Inconsistent findings . . . . .	133
5.4.8 Variables that have adjusted ORs under lower than 1 . . . . .	135
5.4.9 Limitations on the analysis method . . . . .	136
5.5 Qualitative Findings . . . . .	137
5.5.1 Positive messages . . . . .	138
5.5.2 Complains and negative comments . . . . .	139
5.5.3 Potential future development- <i>Story sharing and networking</i> . . . . .	140
5.6 General Discussion . . . . .	142
5.6.1 Reflection on sampling through Mturk . . . . .	142
5.6.2 A critical path towards the development of a preventive intervention for PGD . . . . .	143
5.6.3 Conducting factor analysis (principal component analysis) to further reduce the dimension of predictive factors . . . . .	143
5.7 Implementing the Screening Method in EtG . . . . .	143
5.7.1 The formula for implementation in EtG . . . . .	144
5.7.2 Designing the research deliverable, Empowered to Grieve (EtG) . . . . .	146
5.7.3 The practical consideration of implementing EtG in the real world . . . . .	149
5.8 Limitations and Future Research Opportunities . . . . .	149

## CHAPTER 6 DISCUSSION AND CONCLUSION 153

6.1 Insights into HCI field . . . . .	153
6.1.1 More needs to fulfill in addition to attending the mental disorder . . . . .	153

6.1.2 Conducting activities that will exhibit (positive) changes on the bereavement experiences . . . . .	154
6.1.3 The bereaved's online empowerment experiences. . . . .	156
6.2 Insights into Psychology . . . . .	157
6.2.1 The further narrow down of potential variables. . . . .	157
6.2.2 Seven variables that exhibit high correlation to PGD. . . . .	158
6.2.3 Insignificant confirmed risk factors in the predictive model. . . . .	158
6.2.4 Predictors that are only significant risk factors under certain circumstances	159
6.3 Ethics Considerations and Study Design. . . . .	159
6.4 Insights into administering an online questionnaire study on MTurk . . . . .	160
6.4.1 The necessary functions to be included in the program . . . . .	161
6.4.2 Recap: steps to evaluate the answers . . . . .	163
6.5 Conclusion . . . . .	163

## CHAPTER 7 REFLECTIONS, LIMITATIONS AND FUTURE WORK 166

7.1 Reflections. . . . .	166
7.2 Evaluate EtG in terms of the thoughtfulness of the technology . . . . .	168
7.3 Limitations . . . . .	168
7.3.1 Assessing the effect of empowerment. . . . .	168
7.3.2 Study samples . . . . .	169
7.3.3 Require a longitudinal study for further validation . . . . .	169
7.4 Future Work. . . . .	170
7.4.1 Future work on the screening model . . . . .	170
7.4.2 Future work on EtG . . . . .	170
7.4.3 Future work on the bereavement-related studies . . . . .	171

## REFERENCES 173

## CURRICULUM VITAE 186

## APPENDICES 187

## List of Figures

Figure 1.1 The four most common patterns of bereavement process . . . . .	5
Figure 3.1 Overview of the two phases of study. . . . .	26
Figure 4.1 The entry page of My Grief Journal . . . . .	52
Figure 4.2 The demo visualization of keywords and the valence of the keywords . . . . .	52
Figure 4.3 GIFT entry page . . . . .	58
Figure 4.4 GIFT slider scale . . . . .	58
Figure 4.5 GIFT feedback . . . . .	58
Figure 4.6 A slider for Likert Scale answer. . . . .	59
Figure 4.7 Slider response after an answer is indicated. . . . .	59
Figure 4.8 The responsive slider on a mobile device . . . . .	59
Figure 4.9 When user selects "N/A," it means that the statement could not apply to his/her situation . . . . .	59
Figure 5.1 Diagram of the data structure. . . . .	86
Figure 5.2 The digital signature of informed consent form . . . . .	98
Figure 5.3 Displaying the suicidal hotline . . . . .	98
Figure 5.4 Warning from the attention checker . . . . .	101
Figure 5.5 Acknowledge the completion. . . . .	101
Figure 5.6 The visual feedback of the score . . . . .	102
Figure 5.7 The visual feedback of multiple scores. . . . .	102
Figure 5.8 The vertical layout of GIFT interface. . . . .	105
Figure 5.9 Accordion menu . . . . .	105
Figure 5.10 Welcoming message at the beginning of the study . . . . .	106
Figure 5.11 The navigation between scales . . . . .	106
Figure 5.12 The slider design for Likert Scale items. . . . .	108
Figure 5.13 The responses when participant hovers and clicks on the slider. . . . .	108
Figure 5.14 Flow of participant numbers in each stage of the study . . . . .	113

Figure 5.15 Welcoming page of EtG . . . . .	148
Figure 5.16 Total 16 questions of the questionnaire . . . . .	148
Figure 5.17 The feedback displayed with visual result . . . . .	149
Figure 5.18 Downloadable figure with feedback . . . . .	149

## List of Tables

Table 3.1 The overview of participants . . . . .	26
Table 3.2 The overview of themes. . . . .	29
Table 4.1 Confirmed risk factors suggested in review papers [128, 218] . . . . .	54
Table 4.2 Groups of variables . . . . .	54
Table 4.3 Assessment instruments . . . . .	57
Table 4.4 The socio-demographic data of the protocol analysis participants. . . . .	62
Table 4.5 Participants' assessment of the experiences of answering the questions and the relevancy of the questionnaire for the Basic Information section . . . . .	63
Table 4.6 The assessment of each questionnaire. . . . .	65
Table 5.1 The title and introduction of the questionnaires in the app. . . . .	87
Table 5.2 The grouping criteria and feedback of PG-13 . . . . .	89
Table 5.3 The grouping criteria and feedback of CESD-R . . . . .	91
Table 5.4 The grouping criteria and feedback of PCL-C . . . . .	92
Table 5.5 The grouping criteria and feedback of CD-RISC-10. . . . .	94
Table 5.6 The grouping criteria and feedback of ISLES-SF. . . . .	94
Table 5.7 The grouping criteria and feedback of PTGI . . . . .	95
Table 5.8 List of attention checkers and the criteria. . . . .	99
Table 5.9 The socio-demographic characteristics of sample population (n = 611) . . . .	114
Table 5.10 Odds ratio of background factors with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases). . . . .	117
Table 5.11 Model 1 with background factors (n=379 selected cases / 232 unselected cases) . . . .	119
Table 5.12 The contingency table for cross-validating the performance of Model 1. . . .	119
Table 5.13 Odds ratio of bereaved-related risk factors measured respectively by BRISQ and CGRF with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases) . . . . .	121
Table 5.14 Model 2 with background factors and bereavement risk factors (n=379 selected cases / 232 unselected cases) . . . . .	124

Table 5.15 The contingency table for cross-validating the predictive power of Model 2 . 125

Table 5.16 Other bereavement outcome factors (n=379 selected cases / 232 unselected cases) . . . . . 126

Table 5.17 Model 3 with background factors, bereavement risk factors and bereavement outcome factors (n=379 selected cases / 232 unselected cases). . . . . 126

Table 5.18 The contingency table for cross-validating the predictive power of Model 3 . 127

Table 5.19 Three models with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases) . . . . . 128

Table 5.20 Comparing the Area Under the Curve (AUC) with ROC test. . . . . 130

Table 5.21 Predicted probability of 4 cases. . . . . 146

The links to both study websites are:

Grief Inquiries Following Tragedy (GIFT)

<https://gift.designempowerment.com>

Empowered to Grieve (EtG)

<https://www.designempowerment.com>

# WATER

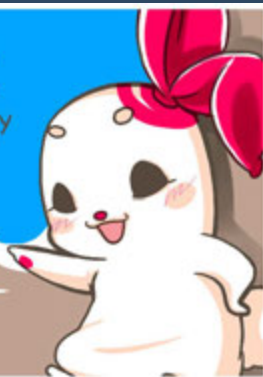
Some colleagues believe that hard water in the Netherlands causes Dutch men to lose hair



Originally published in  
Oranje Express

Aug 13, 2015

Hey, all. I am Lave. This comic strip is about the culture shocks and funny life events I have encountered in the Netherlands.



正妹同事

Some say that the water in the Netherlands is quite hard and can cause hair loss?



Oh, really? I've been drinking for 20+ years, but I am not concerned about hair loss.

Oh...

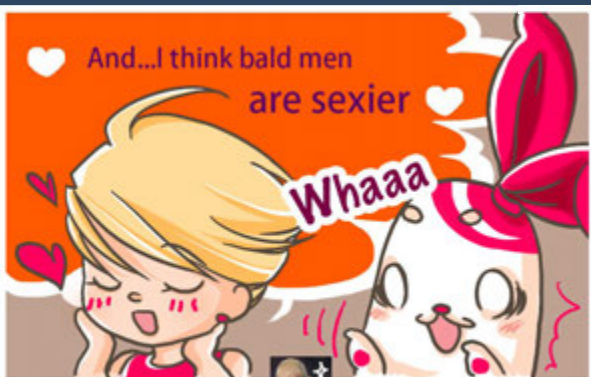


♥ And...I think bald men are sexier ♥

Whaaa



Yeah, I am SEXY!





## Chapter 1 Introduction

As individuals' work and social activities increasingly mediated by technology, individuals' everyday experiences become more and more intertwined with the interaction experiences with technology. In the bereavement context, death and mourning are perceived as more public, digital and even collective [1]. It demonstrates that interacting with technology not only mediates our activities, but also nudges new patterns of thinking and responses to various experiences in our end of life and bereavement experiences. Following Massimi's conceptualization of a more "thanatosensitive" technology (thanato is referring to thanatology, the scientific study of death and the practices associated with it), exploring how technology could contribute to supporting and attending the needs of the bereaved is now becoming a subject of several Human-Computer Interaction (HCI) researchers [2, 3].

Psychology is known to be a forerunner in identifying the needs in the bereavement process, defining the normal and maladaptive responses to the loss of a loved one [4-6] and developing the effective interventions to treat the chronic grievers [7-10]. In the HCI field, the insights derived from bereaved users' interaction with technology also unfolds plenty of interesting directions for further research and development. The examples include the digital legacy [11-14], collective and online memorialization [15-18], and the continuous bonds with the deceased on the internet [19-21]. However, from the HCI field, little attention is placed in the clinical aspects of bereavement, in which the researchers from psychology are mainly interested in and the effect of bereavement supporting programs mostly warranted. Understandings from the user sides open a gate to re-designing different dying and mourning experiences but could fall short in addressing the needs to assist the severely bereaved individuals, which will be the major incentive of this thesis.

This thesis is driven by the desire to explore how HCI and psychology researchers can work hand in hand to address the needs of empowering and supporting the chronically bereaved.

It means that this thesis will start by identifying the potential research opportunities posited by bereavement-related studies and attempt to explore how technology can play a role in motivating a solution.

## 1.1 Problem Definition and Research Opportunities

### 1.1.1 The context of the research

Bereaving the death of a loved one is a spiritual journey that is often accompanied by emotional distress, life-changing choices, and effortful cognitive reconstruction [22-25]. A survey conducted by Holmes and Rahe (1997) places the death of a loved one at the top of the stressful life events inventory (with the death of a spouse as the most stressful life event) [26]. Furthermore, losing a loved one is never a rare event. Most of the individuals, by the time they reach colleges, will experience at least one loss experience (60% loss of a friend and 81.3% loss within their extended family) [27], which reflects the prevalence and ubiquities of loss and grief experiences.

On the other hand, the continuous evolution of bereavement studies and the introduction of positive psychology introduces a multidimensional perspective on the bereavement experiences [28-31]. By acknowledging the opportunities of the enhanced meaning of life and resilience [32-36], researchers unveiled a different perspective of bereavement which is more related to post-traumatic growth and meaning reconstruction [37-44]. Psychologists further challenged the necessity to perform grief counseling to the bereaved individuals who are under a natural bereavement course [45-47]. Also, a majority (up to 90%) of bereaved individuals could successfully ameliorate the post-loss sadness and anguish, and, within around two years, gradually accommodate the impact into their ongoing life and continue living a productive life [28].

While most of the bereaved manage to cope with their grief resiliently, previous studies indicated that a group of the bereaved could experience a protracted or complicated syndrome referred to as Persistent Complex Bereavement Disorder (abbreviated to PCBD for convenience in the later paragraphs) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) [48], or Prolonged Grief Disorder (abbreviated to PGD in the later paragraphs, used interchangeably with PCBD to refer to the maladaptation of grief) [49] or Complicated Grief (abbreviated to CG in the later paragraphs) [4, 50] in a variety of bereavement-related studies (for a comparison and review of three related terms, see Maciejewski et al., 2016). To clarify, this thesis mainly adopts PCBD and PGD as the same diagnostic entity for post-loss syndromal grief reaction [6]. The prevalence of PGD among the bereaved population is

around 9.8%, suggesting that one out of ten bereaved adults could develop PGD [51]. PGD is associated with work and social malfunctioning, heightened risk of severe medical conditions, and frequent suicidal ideation [49]. Individuals who developed PGD could also suffer from post-loss depressive symptoms or Post-traumatic Stress Disorder (PTSD) [52, 53]. Burgeoning studies are focusing on this particular group of individuals who need and will benefit from psychological intervention.

### 1.1.2 Problem definition

*Problem: lack of a warranted mechanism to distinguish bereaved individuals who are susceptible to develop PGD in the early phase (particularly within the first six months) of bereavement.*

Given the significant impact PGD exhibits on an individual's physical and mental health, it could not be confirmed until up to six months after the loss [49]. DSM-V indicates that the diagnosis of PGD should not be issued before 12 months after the death of a loved one [48]. Previous reviews questioned the effect of offering psychotherapeutic intervention to the griever who do not suffer from syndromal grief symptoms could not be justified and could even disrupt the natural grief mechanism [45-47]. On the other hand, the amount of time required to confirm a PGD and to offer target treatment for PGD grievers is discrepant with the fact that the psychotherapeutic or other available support may be highly needed in a much more timely fashion. Furthermore, identifying griever who are vulnerable to PGD allows the individuals or clinicians to work on it and to possibly prevent it in the early stage.

Figure 1.1 demonstrates the common patterns of bereavement processes. Six months is an important point when the level of grief between normal griever and syndromal griever start to deviate to a certain degree that differentiates the two groups. Before six months, these two groups of griever both could experience a higher level of grief and emotional distress that are very identical to severe grief patterns [36, 54]. Therefore, six months is the minimum requirement for clearly diagnosing PGD without misinterpreting high level of grief as a symptom of chronic grief. The significant difference between normal griever and chronic griever is that despite the high level of grief in the first six months, normal griever could gradually come to terms of their sadness, and their grief level will decrease as they move into acceptance of the losses; chronic griever could be “stuck” in the process and remain at a high level of grief, which could severely exacerbate their interests of resuming normal social and life pattern [49].

Studies that target on supporting the bereaved during this period (before PGD could be diagnosed) or on preventing PGD at an early stage remained scarce, and there is a pressing need to support vulnerable individuals at the first six months of their bereavement period (for

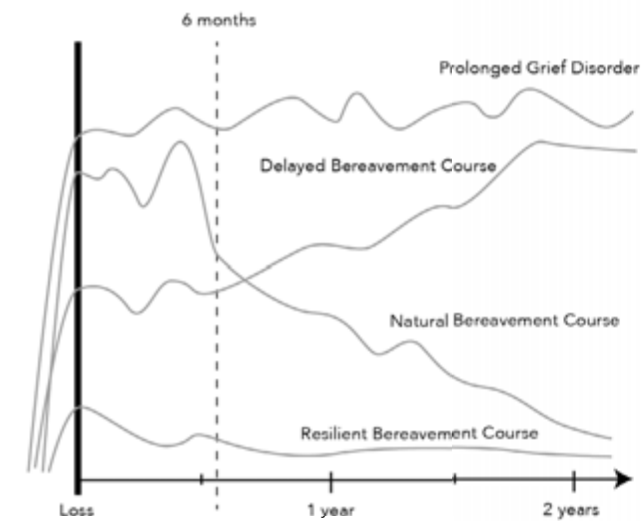


Figure 1.1 The four most common patterns of bereavement process (adapted from G.A. Bonanno, “Loss, Trauma, and Human Resilience: Have We Underestimated the Human Capacity to Thrive After Extremely Adverse Events?” *American Psychologist* 59:20-28)[36]

a review, see Wittouck et al., 2011). The benefit of supporting the individuals who are prone to develop PGD in the long run can be viewed from two perspectives. From the perspective of prevention, although it is less discussed in the bereavement-related literature, grief counselors or health service providers can target on preventing the development of PGD in the early phase before the grief gets “complicated.” From the perspective of treatment, more sophisticated interventions or targeting treatments can be more actively engaged in the bereavement journey and collectively fumble a way through the storm with the griever.

### 1.1.3 Research opportunities

Technology is gaining a proliferated influence on our bereavement-related activities and grief coping experiences, which griever frequently utilize to support their coping needs before referring to psychological interventions [55-58]. The bereaved turn to the online bereavement forum for emotional support and anonymous experiences sharing (Massimi has published a paper describing his explorative design of an online bereavement support forum, see Massimi, 2013) [59, 60]. Social network users are frequently posting reminiscing photos or messages to the deceased loved one and maintaining continuous bonds with the deceased through such conduct.



A deceased loved one's profile can be turned into a memorial page on Facebook [15, 16, 18-20, 61-63]. Funeral companies begin to stream memorials or funerals online [64, 65]. Psychologists are offering grief interventions or advice through email or personal page [7, 8, 66, 67]. These examples demonstrate the potential of technology to support the bereavement-related activities.

However, despite some preliminary findings in the recent psychological and (HCI) studies, the implementation of technology to support preventing the development of PGD remain scarce. This evidence posits a research opportunity to identify the potential design opportunities to implement technology to support preventing the development of PGD promptly.

## 1.2 Research Questions

Based on the problem definition, the overarching research question is **“How can technology contribute to empowering the bereaved internet users in the first six months of bereavement?”** The research question is divided into three sub-questions that define the major phases of the study.

Phase 1: What is the role technology plays to attend the needs of the bereaved internet users in the process of coping with loss?

Phase 2: How to gather the data from the bereaved internet users to support the design of the screening method?

Phase 3: How to design an Internet-based screening method that empowers the bereaved to make clinically-related decisions in the first six months of bereavement?

## 1.3 Research Objectives

The overarching goal of this research project is “to design an Internet-based Product-Service System (PSS) for screening the prolonged and intense grief in the first six months of bereavement.” According to the research questions, three research objectives of the thesis is defined into the following three building blocks:

- (1) to investigate the technology design opportunities to attend the needs of the bereaved internet users
- (2) to design an Internet-based data gathering system that can be implemented in collecting the data for developing the screening method.
- (3) to build a screening method of PGD that is empirically tested and can be embedded in

an internet-based PSS

## 1.4 Thesis Organization

This thesis is composed of seven chapters that aim to investigate how to design an Internet-based screening method for PGD in the first six months of bereavement. In this chapter, we briefly define the research questions and objectives that will ground our future studies design in the following steps. Chapter 2 accounts for a literature review on bereavement theories based on psychology literature and reviews and defines the prolonged and intense form of grief that this research is targeting on.

To provide a social and technological context in which the internet-based PSS would be used, Chapter 3 reports an explorative study that maps the context and activities in which the technology could contribute during the bereavement process both from literature and a qualitative study. The result of this study reveals what coping-oriented activities can be conducted by the bereaved internet users, and how some of the activities are mediated by technology. We further compare the results with the literature to discuss the potential contributions of this study.

From the previous understanding of psychological literature, there is a lack of screening methods for distinguishing grieverers that may benefit from the clinical intervention before their susceptibility to prolonged and intense grief could be confirmed, which requires a minimum six months to be identified [49]. Chapter 4 presents the development of an internet-based PSS, Grief Inquiries Following Tragedy (GIFT), to gather data and user experiences from the bereaved internet users, followed by deploying the PSS to build the predictive model for implementing on the final screening method, Empowered to Grieve (EtG), in Chapter 5. We conclude this book with the discussion and reflection of study results (Chapter 6) and future research opportunities (Chapter 7).

### 1.4.1 Publications and prior work

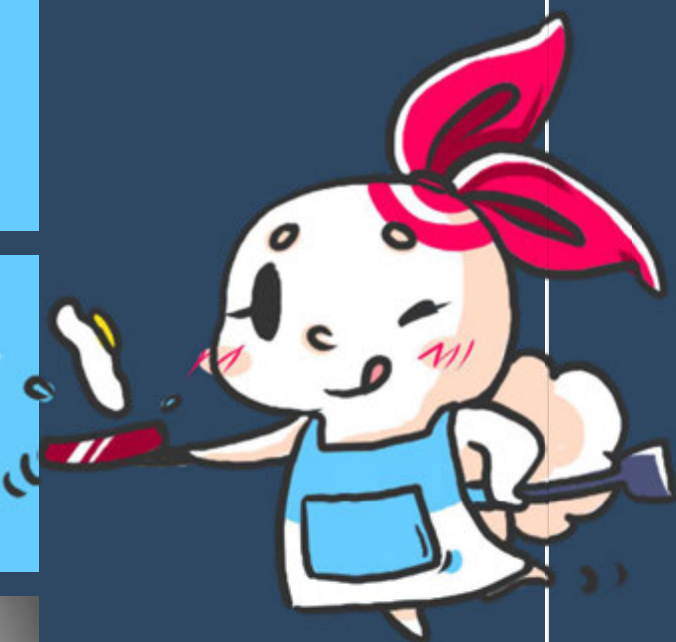
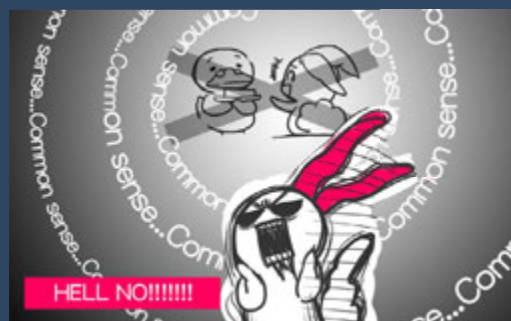
Portions of the thesis have been published previously at academic conferences as abstract, poster and papers.

- The Phase 1 study has been presented at the Futures of End of Life as a poster, and published in the conference proceeding of Dying and Death '17 [68].
- The Phase 2 study has been published at the DesForm 2017 proceeding [69].



# BIRTHDAY SURPRISE

In Netherlands, they make the birthday celebrants "pay."



Originally published in  
Oranje Express  
Oct 5, 2017

## Chapter 2 Literature review

The goal of this thesis is to design technology that can empower the bereaved internet users in the first six months of bereavement, especially for the bereaved who are prone to experience prolonged and intense grief. In Chapter 2, we proceed with an overview of the bereavement theories from psychology and identify the difference between the normal grief and the PGD, the maladaptive reaction following the death of a loved one.

### 2.1 An Overview of the Bereavement Theories

A variety of bereavement theories were developed in the past century to comprehend the process of bereavement and facilitate the necessary knowledge to attend the needs of the bereaved. It is important to note that some theories have a major impact in defining the pathological form of grief and have speculated the potential approach to develop interventions for PGD. This section will review some representative bereavement theories that contribute to set a cornerstone for clearly defining PGD and developing interventions for it.

#### 2.1.1 The grief work hypothesis and the traditional approach of understanding grief

##### Freud's grief work hypothesis

The earliest initiative to form a bereavement theory is inspired by Freud's [70] manuscript, "*Mourning and Melancholia*," in which he believed that mourning process is a gradual withdrawal of emotional energy (decathecting) from the deceased and invest it in new relationships or life goals. Like Freud, Lindemann [71] also suggested that the adaptation of grief is marked by successfully relinquishing the emotional bonds to the deceased. Hence, to actively "work through" grief by attending the emotions, memories and thoughts associated with the loss is

crucial for coping with grief. Individuals who fail to complete the grief work and let go of the emotional bonds with the deceased are considered pathological. Despite its lack of clarity and validity, Freud's acknowledgment of actively working through grief (mourning) has exhibited a major influence on many following grief theories.

##### Bowlby's attachment theory and the four stages of grief

Another essential theoretical framework that contributes to understanding the rationale of grief responses is Bowlby's attachment theory [72-74]. Attachment refers to the instinctive affectional bonds formed between a child and his/her primary caregiver (or parent) to ensure survivability, which is later found to apply to adult relationships, too [75, 76]. Bowlby speculated that the attachment with the caregiver is a natural survival mechanism which facilitates an individual's emotional development and security, and, if potentially threatened, could trigger powerful attachment behavior (such as crying or angry protest) to resume the proximity. Therefore, a permanent loss of the affectional bonds could spawn severe grief response, and the survival individuals need to adjust to attenuate the dysfunctional attachment behavior.

Bowlby and Parkes (1970) further broke down the grief process into four stages of reactions, including numbness, yearning for bereaved, depression and reorganization [77]. The bereaved go through the four stages of reaction to reorganize the emotion and life patterns disrupted by loss and to return to their former interests. First stage comprises of numbness and shock which serves as the protective mechanism to blunt the intense emotion and buffer the stress. The bereaved reach a realization that the loved one is permanently lost before they proceed to the second stage, yearning and searching for the deceased. A myriad of emotions are experienced and expressed during this stage. Typical reactions include weeping, anger, anxiety, preoccupation, and self-reproach. When the emotions become less intense, individuals accept the reality and move to the third stage, depression. The bereaved need to bear a life without the loved one, and they are confronted with loneliness and disinterest in other social activities. After the bereaved have successfully go through the third stage, the grief recedes, and the intrusive memories become less poignant. The bereaved start reorganizing life patterns, discovering new goals, establishing other social relationships and return to a new state of "normal." Successfully going through the four stages of grief will ensure an individual's recovery and avoid severe preoccupation, and mental illness ensued by the loss.

Bowlby and Parkes's view on grief process, although not prevalently acknowledged, has significantly inspired one of the most popular stage model proposed by Kübler-Ross, the five stages of grief.

##### Kübler-Ross's five stages of grief

As one of the most popular grief models that characterize the shared understandings of grief process

by the general public, Kübler-Ross's five stages of grief was first developed in her experiences of working with the dying patients [24, 25]. In her highly influential book *On Death and Dying*, she explains how the patients go through denial, anger, bargain, depression, and finally acceptance in the terminal phase of life. This model has promulgated stage theories of bereavement and has, up until now, been generalized to a variety of grief experiences such as divorce [78, 79], children's responses to a divorce [80] or breakup of a romantic relationship [81]. The five stages model shares many similarities with the four stages model. The bereaved individuals experience denial and disbelief at the first phase to avoid being overwhelmed by the intense emotions. When the bereaved eventually realize the reality, they are often surrounded by the frustration of the reality and hence experience the anger, wanting to justify the circumstances. The anger then dissipates, and the bereaved begin to bargain and hope to revert the situation, where the third stage fades in. The bereaved yearn for the deceased to return and hope to negotiate a way out of the reality. In the fourth phase, the reality eventually bounces back, and individuals have no choice but to adjust their emotions and cognitive appraisal. The fourth stage is characterized by depression and feeling of emptiness. Individuals force their attention on the present and struggle to live a life without the loved one. Then there comes the acceptance in the final stage of grief.

Although stage-based model seems to be a simplistic approach to practice and training, it has received a major criticism such as lacking the empirical evidence of each stage, failing to consider social and cultural factors, overly reducing grief to a linear process and failing to address the diverse responses following loss of a loved one [82, 83].

### **Worden's tasks approach**

Despite the strong influence of stage concepts, there was a noticeable demand for different perspectives. Worden's work has marked a valuable attempt to go beyond the stage approach and integrate the concept from developmental psychology [84, 85]. Worden believed that grief is a cognitive process comprised of several tasks to reprocess and readjust the thoughts of the lost, the experience and the world, which is a new interpretation of Freud's grief work. He proposed four tasks grievers should achieve to regain emotional equilibrium and move on with life. Although there is the natural sequence of the four tasks, Worden did not suggest that these four tasks have a linear relationship such as the stage approach. These four tasks are namely:

- To accept the reality of the loss
- To process the pain of grief
- To adjust to a world without the deceased
- To find and enduring connection with the deceased in the midst of embarking on a new life

Completing tasks encourages mourners to try to keep grief in a manageable scope and enables clinicians to offer hopes that there are ways through it. Worden's approach is flexible and highly applicable to both mourners and clinicians (see the discussion of Worden's model in Wright et al., 2008, p. 352).

### **2.1.2 The recent development on bereavement models and bereavement interventions**

Plenty of critiques have been raised towards the traditional approaches of grief such as its psychological reductionism, lacking applicability to different cultures and the over generalization of grief treatment, resulting in a need of more dynamic and integrative approaches that encompass the dynamic nature of grief experiences (see the review of Thompson, 2002, p.3 to p.10) . Contemporary researchers have come to view grief in a more multi-dimensional perspective. Stroebe and Schut [87] proposed the Dual Process Model to address the limitation of the earlier stage-based approach and integrate the new perspective on grief work hypothesis from Worden's tasks approach. Other researchers have studied the variety of grief experiences such as meaning-making [41, 88], continuous bonds [89, 90] and even positive gains [37, 38]. The experience of momentary positive emotions during the bereavement process was also acknowledged [91-93].

#### **The Dual Process Model of Bereavement**

The Dual Process Model (DPM) is proposed by Margaret Stroebe and Henk Schut to better explain the grief process and address the limitations of traditional bereavement theories [87, 94]. Stroebe and Schut argued against the linear progress of the previous approaches and postulated that an oscillation between two orientations is more accountable to the complexity and diversity of a grief process. The bereaved is believed to constantly move backward and forward between two types of stressors, the loss-oriented and the restoration-oriented stressor. The loss-oriented stressors are related to the emotional challenges and painful feelings caused by losing a loved one, and the restoration-orientation stressors arise when the grievers must attend to a variety of life changes and cognitive crisis. The process of coping with each type of stressors could result in particular types of costs, and alternating between the two orientations could ameliorate the risk of adopting a single strategy for too long (e.g., consecutively ruminating the painful memories).

With its incorporation of Worden's tasks aspect and cognitive stress theory, the Dual Process Model is one of the representative models that contribute to the explanation of pathological grief and establish an additional trajectory to the traditional ones of resolving grief solely through confronting the loss [95].

#### **Meaning reconstruction as the central feature of grieving**



The quest for meaning is a frequent activity for many human beings. As the sociologist, Norbert Elias, indicated in his frequently cited work “*The Loneliness of Dying*,” meaning is constituted by a group of individuals who are dependent on each other [96]. He further argued that due to a higher degree of individualization and restraint from strong emotional impulsion in the postmodern era, the feelings and shared meanings of death and dying are “repressed” from the society. It is, therefore, predictable that postmodern individuals will die alone, which could also imply that postmodern individuals will bereave alone. The death of a significant figure could disrupt the relationship, from which an individual gains meaning and security from, and postmodern individuals are most likely to find meanings alone, too.

Disregarding whether postmodern individuals will bereave or find meanings lonely, finding meaning in the midst of bereavement (or suffering) is crucial and has been recognized as one of the resilient characters of human beings [97-101]. Viktor Frankl [102], a psychiatrist and a Holocaust survivor, has explicitly pointed out that although the given circumstances confront us with unchangeable suffering, human beings are still free to choose their attitude in perceiving the circumstances. Death of a loved one could significantly challenge or disrupt ones’ “assumptive world,” a belief of a predictable life, a benevolent universe and a worthy self that would ground and secure an individual’s flourishing [103]. According to Robert Neimeyer (2001), meaning reconstruction is of crucial importance in restoring the coherence of one’s narratives. To integrate the changes into the griever’s pre-existing scheme of worldview requires griever to reconstruct their life narratives in a personally meaningful manner and to renegotiate a worldview which could accommodate these changes [88, 99, 100, 104, 105]. Meaning reconstruction is highly associated with continuous bonds and post-traumatic growth experiences [37, 38] and could significantly contribute to enhancing griever’s post-loss psychological well-being [29, 30, 83].

### **Continuous bonds with the deceased**

Although Freud’s view on disengaging the attachment with the deceased has been called into question for a long period, it has yet been fundamentally challenged until the contribution of the continuous bonds perspective. A growing number of researchers and empirical studies have proven that the emotional bonds with the deceased do not disappear, but are maintained in a different form in the bereaved’s minds and could potentially promote a healthy adjustment to the loss [106-109]. This valuable perspective has unfolded a new dimension of our loss experiences and lifted the long-held prejudice that maintaining an emotional connection with the deceased is maladaptive. It also explains why the bereaved attempt to communicate with the deceased on the internet and are constantly interacting with each other on the deceased’s profile pages [1].

### **Resilience in bereavement**

George Bonanno’s perspective on human resilience is highly informative to our overall understanding of bereavement reactions [33, 110-112]. Bonanno proposed the resilience trajectory following a major loss, in which he emphasized that most of the bereaved, unlike the severely distressed griever treated by the psychologists, do not develop chronic or prolonged distress and can continue to live a meaningful and functioning life. Burgeoning studies have evidenced that positive emotions (or laughter) can frequently be observed and are beneficial for sustaining the griever’s post-loss psychological well-being [91, 113]. The effect of performing grief counseling to griever who are at their normal bereavement course was questioned [47]. As Neimeyer and other researchers empirically studied and warned, there is insufficient evidence that supports the positive effect of performing grief counseling to the normal griever; instead, it could even disturb the natural grieving process and cause a deleterious effect [45-47, 114]. This thread of thinking is of vast importance for researchers and psychologists who aim to develop interventions for or support the griever because identifying the griever who will benefit from the psychological intervention is critical before offering it to the general griever (see 2.2.3 for a more detailed discussion).

## **2.2 The Maladaptive Reaction in Bereavement**

Whether there is a condition or disorder related to bereavement has triggered ample debates in the past two decades. Grief, despite the emotional suffering in the process, also serves as a natural mechanism to regulate emotion and pay respect to the deceased [95, 115]. It is an effortful journey but fundamental in the light of coming to terms with the loss and fumbling a way through the potentially challenging process. Researchers affiliated with other mental disorders tend to question the necessity to coin a new mental disorder related to bereavement. In reality, DSM-V has remained conservative to this concept and listed PCBD in the section of potential conditions that require further research [48]. Whereas practitioners or psychiatric researchers could acknowledge ample evidence and need for a well-defined disorder to clarify the degree at which grief becomes “pathological” [54, 116-119].

The necessity was further reinforced after several researchers raised the concerns about the efficacy of grief counseling. It is argued by Allumbaugh, Neimeyer, Jordan, Bonanno and other researchers that not every griever benefits from bereavement-related interventions; whereas bereavement-related interventions can certainly contribute to support individuals who experience the prolonged and complicated form of grief [9, 45-47, 83, 110, 120-123].

This section discusses the criteria for identifying the pathological or intense form of grief,

Persistent Complex Bereavement Disorder (PCBD) or also referred to as Prolonged Grief Disorder (PGD) or Complicated Grief (CG). PCBD and PGD are two different terms that jointly address the nature of the syndrome [6], and CG appears to be another frequently used term for it [54]. Hence these three terms could be used interchangeably in this thesis.

### 2.2.1 Diagnosis of PGD

Although PGD is not yet recognized as a psychiatric disorder, it has been included in Diagnostic Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) as one of the conditions for further study [48] and will be included in ICD-11 as a mental disorder [124]. DSM-V, as one of the most authentic diagnosis reference for mental disorders, provides a set of informative and unbiased criteria for PCBD, stating that a PCBD diagnosis can only be issued after a minimum of 12 months since the bereavement occurred. Prigerson et al. claimed that a diagnosis of PGD takes at least six months to be issued. PG-13, a diagnostic tool developed by Prigerson et al., has suggested five necessary criteria for identifying PGD [49, 125, 126]. These five criteria are respectively (A) event criterion (the experience of loss of a loved one), (B) separation distress (persistent yearning and intense sorrow), (C) duration criterion (at least 6 months after the loss), (D) cognitive, emotional and behavioral symptoms (difficulty accepting the loss, disbelief or emotional numbing over the loss, identity crisis or difficulty trusting others), and (E) impairment criterion (experiencing social or occupational dysfunction). The b criterion is characterized by persistent yearning (#1) and intrusive sorrow (#2). The D criteria from PG-13 corresponds to most criteria in the C category proposed in DSM-V, which includes: avoidance of reminders or avoidance of thoughts, activities, or situations (#4), feeling shocked by the loss (#5), confusion about one's role in life (#6), difficulty accepting the loss (#7), inability to trust/detachment from others (#8), bitterness related to the loss (#9), difficulty to move on (#10), numbness/absence of emotion (#11), feeling that life is empty (#12). To be diagnosed PGD, criteria a, c, e must all be met, and individuals must experience both symptoms at least once a day for b criteria and at least five symptoms in an intense degree of the d criteria.

### 2.2.2 Epidemiology

The prevalence of PGD has received less attention in comparison to the interests of clarifying the symptoms and developing interventions for it. It could be methodologically challenging to investigate the prevalence of PGD among the general population and across different cultures. DSM-V suggested a prevalence of 2.4% to 4.8% of PCBD in the general population [48]. The conditional prevalence, also known as the proportion of the PGD griever among the grieving population, is more meaningful for the bereavement-related researchers. According to Maercker and Lalor, various studies implied that around one-third of all bereaved could develop PGD [54].

Because there are various circumstances of loss, some of the potentially traumatic experiences or context could significantly influence the grief intensity. Shear [127] claimed that the conditional prevalence of complicated grief among a particular group of griever (e.g., individuals who lost romantic partners or parents who lost children) could range from 10 to 20%, or even higher. This number is also proven to be higher among female griever [128, 129]. The meta-analysis of Lundorff et al. (2017) indicates that the prevalence of PGD is 9.8% among the bereaved population [51]. Although more studies are needed to inform the field about the general/conditional prevalence of PGD among different populations or cultures, it is worth mentioning that current studies have implied that PGD could be developed among a notable proportion of griever.

### 2.2.3 Further threads in PGD treatment research

Two concerns related to PGD are also worth discussing, the controversies on the efficacy of bereavement intervention and the limited effectiveness of the preventive intervention for PGD.

#### Skepticism on the efficacy of bereavement intervention

Allumbaugh and his colleagues (1999) questioned the effectiveness of grief therapy through their meta-analysis paper, in which the result has failed to support the effectiveness of bereavement intervention. They ended up suggesting that providing support to clients who self-referred to the treatment could acquire a more favorable result. The following reviews and studies also yielded similar conclusion on the ineffectiveness of grief therapy on the general bereaved individuals [9, 45-47, 83, 110, 120-123]. Neimeyer even warned that grief intervention, when performed without cautious selecting, could disrupt the nature bereavement process. It is convincing that providing intervention to the griever who are going through a natural bereavement course does not warrant a positive effect. On the other hand, Wittouck and her colleagues (2011) have suggested that grief intervention could mostly contribute to reducing the complicated grief symptoms. In general, bereavement theories are constantly evolving and developing, and so are the grief interventions. Bonanno *et al.* (2011) have further proposed four patterns of bereavement process, in which he argued that individuals who experience minimum or normal degree of grief would not benefit from bereavement intervention; or rather, forcing normal griever to engage in the same coping process could exacerbate or disturb their natural coping mechanism. Determining if a griever is at risk of developing the protracted or complicated form of grief is of primary importance to facilitate their bereavement processes.

#### The limited effect of preventive intervention for PGD

PGD could cause severe psychological and physical health consequences and social and functional impairment. Although there are valid measures to distinguish the complicated

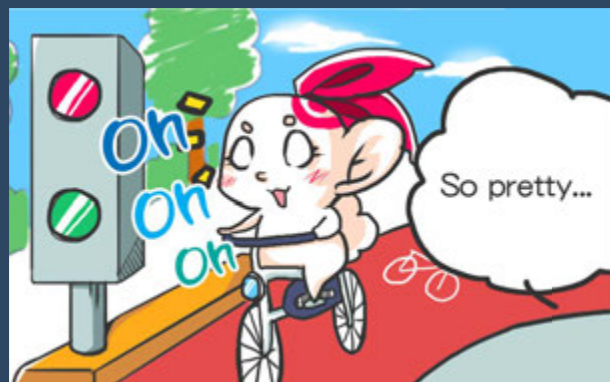
grievers from normal grievors, a minimum period of six months is mandatory to make the diagnosis (see previous literature review). In the situation which the bereaved is at higher risk of developing PCBD, early intervention or preventive intervention might be beneficial in a more timely manner. A meta-analysis done by Wittouck et al. (2011) pointed out that the preventive treatment for bereavement has not yielded significant effect [121, 123], and many preventive studies failed to claim positive results. Bereavement treatment has been significantly informed by the development of Post-Traumatic Stress Disorder treatment, but the prevention of PGD has not [54]. Concentrating on preventing PCBD could be highly valuable to support individuals who are vulnerable to PGD in a more timely manner, and to reduce the risk of developing it in the future.

To sum up, one common point across the various theories of bereavement is that they all endorse the fact that the bereaved could feel “stuck” in the process of bereavement for a protracted period, disregarding if it is caused by failing to reconstruct meaning, having difficulty oscillating between two orientations or being unable to reach the acceptance of the death of loved one. This maladaptation to bereavement is later referred to as PGD, and the diagnosis of PGD requires a minimum of six months. It is known that normal grievors should follow their natural bereavement process and determine who will benefit from the clinical intervention is of imperative importance. A critical path to determine who will benefit from the psychological intervention is to predict the bereaved’s vulnerability to developing PGD in the earlier phase of bereavement. The benefit of developing this predictive method is that the potentially prolonged grievors could receive clinical support more promptly and the psychological resources can be administered to the individuals who need them the most.



# FLIRTING

Apparently, having a fancy bike is ten times more important than having a good look in Netherlands.



CAN YOU PLEASE LOOK AT THE BEAUTY?!?!?



Originally published in  
Oranje Express

Dec 3, 2017

## Chapter 3 Identify the Activity-based Design Opportunities in the Bereavement Context

### 3.1 Introduction

Technology is widely applied in various phases of human lifespan, and designing technology to be more thanatosensitive has become a subject for a group of HCI researchers [1, 2, 131]. However, little is known regarding what role(s) technology plays in the process of coping with loss and to what extent technology engages in the griever's post-loss coping activities. This chapter reports an explorative qualitative study to investigate how technology is engaged in fulfilling the bereavement needs of the bereaved internet users.

Technology frequently mediates our everyday life activities and exerts an increasing influence on the users' behaviors and thoughts [132]. Hence, understanding what coping activities can be potentially mediated by technology can be an effective approach to investigate the role(s) technology plays in the bereavement coping process. This chapter begins by conducting a review of intentional activities that contribute to coping with loss and the relationship of activities and individual's well-being from psychological perspectives. Section 3.2 outlines the activities that exhibit a potential to influence the coping results and discusses the relationship between intentional activities and individuals' well-being. To gain knowledge from HCI perspectives about how technology is involved in everyday life activities, section 3.3 addresses the framework introduced by Activity Theory as the base for further exploring technology-mediated activities. Following section 3.3, section 3.4 presents a qualitative study designed to investigate the role technology plays in the coping process together with the analysis conducted to retrieve insights. The following section reports the results and design implications from the qualitative study with 12 bereaved participants, and we discuss

the findings in section 3.6 and concludes the chapter in section 3.7 with the limitations and contributions of the study.

### 3.2 Defining Activity

In the bereavement context, coping process refers to the process of confronting and managing the stressful situations, and Lazarus and Folkman define coping as thoughts and behaviors that people use to manage the internal and external demands of situations that are appraised as stressful [133, 134]. In other words, a coping process can involve various behavioral and mental activities, which is how we operationalize the concept of activity in this study.

#### 3.2.1 Activities in the bereavement literature

The process of adapting to the emotional, identity and life changes post-loss requires the bereaved to conduct various mental and behavioral activities, which are often referred to as the activities to cope with loss [87, 93, 135, 136]. To better understand what kind of activities are usually conducted to cope with loss, we reviewed the literature related to coping strategies, stress buffering and responses to loss and grief to acquire a holistic understanding of individuals' journey of coping with loss. Note that we excluded literature that discusses psychological treatments and external therapies to reduce the scale of coping to an individual level. Behaviors or thoughts that are considered symptoms or reactions to grief (such as ruminating or bargaining) are also excluded because this study intends to concentrate on intentional activities that can be initiated and managed by the bereaved. The review resulted in seven activities that are often conducted by the bereaved to cope with grief. Understanding these activities helps to situate the HCI researchers in the bereavement context and to further explore the roles of technology in the process.

##### *Manage emotions*

Emotional distress is a frequently observed experience in grief [119]. Acute emotional distress is one of the diagnostic criteria for PGD [48, 49, 54]. Hence, regulating emotions is a frequently studied subject for many relevant researchers [113, 137-140]. Gupta and Bonanno conducted a study to understand the effect of enhancing and suppressing emotional expression and found out that prolonged grievers were less capable of flexibly managing the emotional expression in different contexts [139]. Other discussions published by Bonanno et al. also argued that the ability to flexibly modulate emotional expression can be more desirable in comparison to excessively enhancing or suppressing the emotional expression in the coping process of challenging life circumstances [32, 36, 113, 138]. Expressing emotions means to translate emotional or affective states into verbal or nonverbal behavior. Grieving individuals

express emotions through various manners such as spontaneous responses (crying, shouting and cursing) or narrative reflection (writing and sharing with others) [25, 42, 140]. Suppressing emotion means to control or refrain expression of emotional or affective states [141]. Although it is believed that emotional expression is beneficial for emotion-regulating, recent studies have pointed out that managing improper emotion outburst can be even more helpful for individuals' social life [138].

#### *Avoid*

People can tend to avoid harmful things, which means to keep a distance from stressful thinking or the loss-related context [142-144]. Avoiding can sometimes help the bereaved to prepare for confronting loss since, at the beginning of the loss, the bereaved can feel overwhelmed. However, continuous avoidance of the loss could result in a detrimental effect on the grief process [145, 146].

#### *Seek social support*

External support is an important protective and assistive power for individuals during the loss coping process [136, 147-150]. Many previous studies referred social support as the support from the social network [151-153]. In this study, we consider social network one of the resources of social support. As Vanderwerker et al. (2004) indicated, technological connectedness such as the use of email and internet has the potential to predict the enhanced quality of life among bereaved samples [55]. With the involvement of technology, access to a broader range of information or supporting organizations should also be included in the discussion of resources of social support.

#### *Activities related to meaning reconstruction*

The following three activities (make sense, find benefit and reconstruct identity) are derived from the discussion of meaning reconstruction model proposed by Gilles and Neimeyer (2006). The detailed discussion of meaning reconstruction theory can be found in Chapter 2. In this section, we concentrate on outlining the implications of these three activities in the meaning reconstruction process.

#### *Make sense*

A loss of a relationship can have many different causes such as a car accident or a disease like cancer. Individuals often seek explanations or meanings for the traumas to accommodate the unacceptable loss into their rationale [88, 106, 154].

#### *Find benefit*

Finding benefit means to identify some positive gains and learning experiences after loss. It is a transforming process that allows individuals to reappraise the loss experiences [88, 135,

155].

#### *Reconstruct identity*

Individuals' identity can be shaped by the roles they act in a relationship. Losing a loved one can significantly challenge their long-held identity as the loved one's wife, mother or friend [106, 156]. Many of the bereaved individuals may have to readjust to a new role that is different from what they perceive themselves to be after experience the death of a loved one.

#### *Continue bond*

Death does not disrupt the emotional bonds of the bereaved to the deceased. Researchers suggest that people could still maintain the emotional or spiritual bonds with the lost figures and carry the aspects of the lost figures with them in the post-loss life [107, 157, 158]. Previous literature also supports the potential of technology in facilitating continuous bonds through the social network [19, 61].

Understanding the activities studied by the precedential bereavement literature is a critical step towards understanding the potential association between each activity and the positive outcomes of bereavement. The implication from the psychological literature is that conducting these activities could contribute to post-loss coping and enhancing grievers' post-loss well-being. In the following section, we provide further motivations to focus on activities by reviewing (intentional) activities' strong connection with individuals' well-being.

### **3.2.2 Coping, Intentional Activity and Well-being**

Activity is inextricable in our everyday life experiences and accounts a significant role in our self-development and psychological well-being [159-162]. Perhaps the most reliable evidence that activity could assume a direct (positive) influence on an individual's well-being is from the studies of positive psychology. Lyubomirsky et al. (2005) propose three factors that could contribute to an individual's chronic happiness level. Besides the genetically set point of happiness (accounting for 50% of our happiness) and life circumstances (10%), intentional activities and practices is regarded to account for at least 40% of our chronic happiness level. Furthermore, in comparison to the naturally determined set point and the frequently changing life circumstances, intentional activities demonstrate the best potential to facilitate one's lastingly increasing well-being, and hence interventions are also being developed that facilitate happiness-relevant practices [159].

When it comes to boosting resilience in the stressful life situations, studies in emotion regulation has also indicated the benefit of conducting activities as a redirection of attention and seek pleasure to buffer stress [144, 159]. Taking action to complete a meaningful goal is also considered a critical step in the empowerment process and can further assist resilience

from the stressful context [162, 163].

In one of the studies related to self-evaluation in bereavement, Bauer and Bonanno (2011) indicated that focusing on concrete activities supports an individuals' coping with stress because it directs one's attention to the manageable aspects of life and helps an individual to devise a practical plan for future [98, 105, 164-168]. Their results revealed that the bereaved who more focused on evaluating what they could do during the bereavement process demonstrated lower grief level over time. This evidence is especially interesting when combining with Viktor Frankl's statement that one can at least choose/change his attitude in a given (suffering) circumstances [102]. By focusing on concrete activities and motivating a plan for the future, the individuals spend less attention on the stress itself but attempts to claim our control to negotiate a way of surviving, or better, thriving.

It is important to note that positive results or well-being do not always ensue from every type of activity. As positive psychologist suggest, certain activities are effective to facilitate happiness and buttress resilience [159]. Also, the empowerment model also indicates that the action should be carried out towards achieving a meaningful and power-oriented goal [169]. Not all kinds of activities conducted in the process of coping with stress would assume a favorable result [170]. For instance, it is difficult to consider excessively consuming alcohol an activity that would lead to a positive effect of coping with the sadness of losing a loved one; nor would hurting self be regarded as a positive coping strategy.

To sum up, certain types of intentional activities can exhibit positive impact on an individual's well-being and focus on activities could enhance an individual's self-efficacy in the bereavement process. Below we discuss the foundations of activity theory in the HCI field.

### 3.3 Activity and Interaction Design

#### 3.3.1 Activity Theory and the Activity-Centered Design in HCI

The connection of activity and motive in this paper stems from Activity Theory, which is inspired by the work of the Russian psychologists, Lev Vygotsky [171] and Alexei Leont'ev [172] and has been widely adopted to psychology, computer supported cooperative work or interaction design [173-175]. It is where we will start the discussion of the hierarchical nature of the activity and the potential of utilizing various activities as a systematic approach for exploring technology design in the bereavement context.

Activity Theory has a primary concern for individual development and on how it can be mediated through human engagement with artifacts (tools or sign systems we use) [173-175].

It is especially informative to the field of interaction design as interaction designers/researchers place significant attention on understanding human engagement with technology and how the understanding facilitates more useful and usable design of technology. Recently, the field has observed more and more attempts to conceptualize the "activity-centered," "activity-based," or "activity-centric" design, reinforcing the potential of activity as a more vibrant framing for interaction design that adheres to how individuals use technology in various contexts [132, 176-178].

#### 3.3.2 The hierarchical structure of activity, action and operation

Activity serves as a central role to connect artifacts with our motive and wires the hierarchical structure of a series of purposeful actions and operations [179]. Take the following activity as an example, "Sara complains to her friends after work to vent her frustration." She intended to vent the emotion, and complaining to her friends is the activity chosen by her to fulfill the intention. To realize this activity, several goal-oriented actions could be conducted. Sara should make a call to a friend, invite her to a drink and start describing the event to her friend, all of which are actions that serve the overarching activity and hence comprise a complete experience of emotional venting. During the process of making a call, there are some unconscious operations such as unlocking the cell phone, searching for the number on a contact book and dialing the number. One could not understand the underlying motive from looking at a single action or operation, but activity suggests a rationale to connect them and make them related to each other.

Activity-centered design, which is also a crucial theoretical approach in interaction design, has a primary concern about what tasks or activities must be enabled by the technology or system [173, 180]. Therefore, studying meaningful activities in the bereavement process and their implications on the post-loss well-being of the bereaved can also be informative for interaction design in the bereavement context.

### 3.4 Study Design and Analysis

With the rationale discussed in the above sections, a qualitative study was designed to gain insights from the bereaved internet users and further understand the bereavement context in which the technology will be implemented. In-depth interview was selected as the major study method for its advantage in gaining knowledge about individuals' thoughts and behaviors [181, 182].

The study consisted of two stages: a sensitizing phase and a semi-structured in-depth interview. The first phase prepared and sensitized the participants for the interview, and the



second stage inquired the participants’ coping process by investigating (1) how activities are conducted by the bereaved to cope with loss and (2) what kind of impact do these activities posit on the individuals’ post-loss well-being. The completion of the whole study including analysis took approximately two and a half months and result in around 18 hours of audio data and supplemental data such as photos and multimedia collections shared by the participants. Figure 3.1 shows an overview of the process.

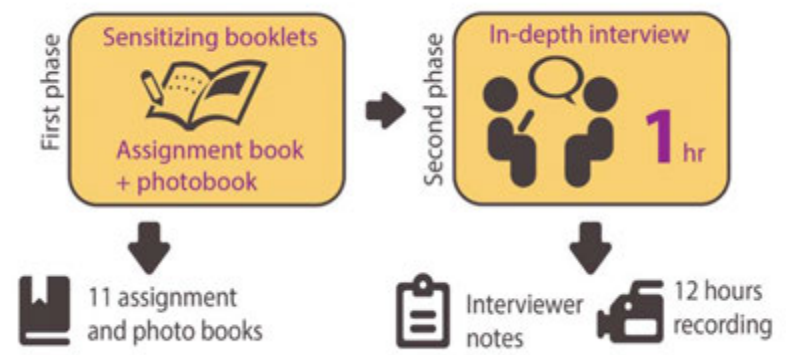


Figure 3.1 Overview of the two phases of study

3.4.1 Participants

Convenience sampling was adopted to recruit the bereaved internet users who exhibit willingness to share their grieving experiences. Participants who have experienced the death of loved ones were recruited through advertisements on the school social network, communities, and email lists. A total 14 participants (10 female and 4 male) voluntarily participated in this study. However, two participants withdrew from the first stage of the study due to failure to complete the sensitizing phase, leaving only 12 participants (9 female and 3 male) completed the whole study. One interviewee chose not to complete the sensitizing booklet but to share the experience anyway. The age ranged from 24 to 52 years old with nine nationalities. Participants possessed various occupations such as students, human resource adviser, sales representative, researchers and school employees. A complete list of participants is displayed in Table 3.1.

3.4.2 Types of loss experience reported

Although most of our participants chose to report the death of their family members or friends, three of our participants did report the death of their pets that were considered equally important as family members. The period after losing a loved one ranged from two months to around 14 years.

Table 3.1 The overview of participants

Participant	Gender	Age	Nationality	Education level	Religion
S01	Male	None	Turkey	Bachelor	None
S02	Female	52	Netherlands	Academic	None
S03	Female	27	China	Master	None
S04	Male	36	Colombia	Post-graduate	Catholic
S05	Female	28	Portugal	Master (currently PhD candidate)	Christian catholic (Roman)
S06	Female	24	Switzerland	Master	None
S07	Female	27	Chile	Master	Catholic-not practicing
S08	Female	31	China	Master	None
S09	Female	36	Netherlands	Master	None
S10	Female	26	Taiwan	Bachelor	Buddhism
S11	Male	27	Netherlands	Academic	Atheistic
S12	Female	26	China	Master	None

3.4.3 First phase of study-sensitizing and preparing the participants

Two booklets were designed for the sensitizing phase, an assignment booklet, and a photo booklet to probe the memories and thoughts of the participants. This step is to prepare participants for the further in-depth interview. The booklets were presented neutrally without suggesting any positive or negative aspects. The assignment booklet contained 6 assignments for 7 days, which mainly inquired the background information about the loss, how did the loss happen, what were their relationships like before and after loss, how the deceased figures played a role in their lives before and after the loss, who were there to support them and how they marked and assessed this loss experience. All the questions were asked in the first-person perspective to engage the participants. For instance, “my loss experience is about (who)” or “after he had left, I created (something) to memorize him” The photo booklet contained ten topics for photos related to the past relationship and current life, whereas, it was not a mandatory assignment.

3.4.4 Second phase of study-interview

The semi-structured interview took place after the completion of the booklets and was entirely recorded with cameras or recording devices. To allow the participants to engage in the conversation and probe their thoughts, the interviewer often started with asking the participants to tell her about the answers they provided in the booklets. Participants were then asked

to describe the activities or strategies they adopted in the process of coping with their grief. Participants were encouraged to utilize the materials they provided in both booklets to elaborate on their answers or add further details to the context and the rationale. We frequently probed participants to reflect on the impact of the particular activities on their post-loss lives. In the end, the participants were invited to offer their opinions on any supportive resources, objects or technologies that contributed to easing their coping process.

### 3.4.5 Analysis

Grounded Theory was implemented as the major approach to analyze the data to extract insights into symbolic activities and the impact of the activities [183]. These significant thoughts and behaviors were referred to as “activities” rather than “coping strategies” for a better operationalization of concept in the design research field.

All the interview materials were fully transcribed and digitalized (e.g., booklets were completely scanned). The files were compiled and stored in NVivo for the convenience of analysis [184, 185]. The transcriptions were analyzed following the reduction tradition to extract the meaningful activities that potentially facilitate positive changes in the bereavement experiences. The coding process included summarizing the transcription into statement cards, clustering the statement cards into codes and categorizing themes from the codes that display similar concepts.

The coding session involved three external coders to ensure the inter-coder reliability [186]. All the three external coders were Ph.D. researchers in the industrial design field and held no background related to psychology study to ensure the objective and reliable result. They were required first to review the statement cards which contained both interview quotes and the summary of the quotes to clarify the potentially confusing statement cards and eliminate irrelevant quotes. The second step was to cluster the statement cards into codes. The codes were further categorized into the three proposed categories. All the cards that were questioned and eliminated were considered disagreements and were used to calculate Holsti's coefficient.

Saturation was examined by importing all the statement cards (including the codes) related to a participant in his/her personal sheet in an excel file [187]. We then checked the saturation by assessing if after a certain number of participants, there were no longer new patterns or codes identified. The saturation was reached after the 6<sup>th</sup> participant.

## 3.5 Result

A total 188 statement cards were reviewed and rephrased by three external reviewers, which

results in 9 disagreed statement cards and 18 re-categorized cards (calculated together like 27 times of disagreement). The inter-coder reliability was calculated based on Holsti's coefficient, and the result was 0.825 (above 0.8 is considered reliable in many other qualitative studies). We here reported the result based on the three themes from our study, meaningful activities, positive changes, and external support. The result meant to describe how the bereavement process and outcomes were embedded in everyday life experiences, including the activities, contexts, (interacting with) products, services, and the surrounding social communities. These are all important factors that designers often consider while generating concepts and hence focusing on these factors related to product service system design could better situate the result in the HCI field.

Table 3.2 The overview of themes

Meaningful actions	Code	Number of cards	Reported from	Card Numbers
Deal with memorable possessions	MA1	10	S2, S4, S5, S8, S10	062, 079, 082, 083, 128, 134, 141, 146, 147, 148
Manage emotion	MA2	10	S1, S2, S3, S4, S5, S7, S8, S10	002, 023, 059, 062, 072, 096, 112, 143, 144, 150, 171, 188
Redirect attention	MA3	13	S1, S3, S5, S8, S9, S10, S12	019, 020, 090, 094, 095, 111, 133, 157, 158, 172, 179, 194, 198
Nurture and comfort self	MA4	5	S1, S2, S7, S10, S11	060, 110, 149, 152, 192
Continue and relocate the bonds with deceased	MA5	18	S1, S2, S3, S4, S5, S6, S12	005, 007, 012, 015, 022, 030, 080, 081, 121, 122, 123, 125, 159, 162, 167, 183, 185, 204
Meaning reconstruction	MA6	18	S2, S3, S4, S5, S6, S7, S9, S11, S12	008, 087, 103, 113, 117, 124, 126, 130, 132, 135, 136, 175, 176, 177, 186, 197, 201, 203
Seek support	MA7	19	S1, S2, S3, S4, S5, S8, S10, S12	003, 061, 069, 071, 073, 077, 078, 092, 093, 097, 098, 104, 154, 155, 163, 169, 182, 205, 206
Perform rituals	MA8	12	S1, S2, S5, S7, S8, S11, S12	001, 011, 013, 014, 091, 100, 119, 120, 137, 168, 178, 208

Meaningful actions	Code	Number of cards	Reported from	Card Numbers
Create memorials or projects for the deceased	MA9	5	S2, S3, S5, S11	006, 129, 131, 153, 174
Conduct altruistic behaviors	MA10	9	S1, S2, S3, S4, S5, S8, S10, S12	024, 027, 058, 068, 070, 105, 107, 145, 199
Denial and avoidance	MA11	7	S1, S3, S5, S7, S9, S11	017, 140, 160, 181, 189, 193, 200
Positive changes	Code	Number of cards	Reported from	Card numbers
Personal growth	PO1	12	S1, S2, S5, S6, S11, S12	026, 028, 054, 067, 088, 101, 102, 106, 108, 156, 166, 207
Self-acceptance	PO2	7	S2, S3, S4, S6	018, 021, 066, 115, 170, 173, 184
Autonomy	PO3	2	S5	139, 209
Positive relations with others	PO4	16	S1, S2, S4, S5, S6, S7, S8	009, 025, 031, 055, 056, 057, 074, 077, 085, 086, 089, 161, 187, 190, 195, 196
External support	Code	Number of cards	Reported from	Card numbers
Social support	ES1	12	S2, S4, S6, S7, S8, S11	010, 075, 076, 084, 116, 118, 127, 138, 142, 151, 165, 202

### 3.5.1 Meaningful activities

Eleven meaningful activities were identified from our study. The criteria for identifying the meaningful activities were to identify the activities or behavioral patterns that facilitate empowerment in the processes. Our result showed 11 activities that were especially meaningful for the bereaved in the process of actively processing and experiencing the negative emotions and reconstructing the meanings in the post-loss life.

#### 1. Deal with memorable possessions (MA1)

The possessions of the deceased loved ones were often left for the griever to deal with. The process of dealing with the memorable possessions frequently involved decision making. In the beginning, the bereaved collected and sorted out the possessions of the deceased loved

one. It was often done by going through the property the deceased used to live or checking the room or closets of the deceased. In case the deceased left digital possessions such as photos and videos, these were also copied to a computer or a hard drive. After having a brief inventory of the possessions, the bereaved were to decide which possessions to keep and which possessions to dispose of. Physical possessions were thrown away, and digital possessions were deleted from the computer or hard drive. In the traumatic cases, S2 even mentioned designating other people to deal with the possessions because they were too emotionally disturbing; *"I threw away all the kitchen stuff and his clothes. I could not touch his clothes, smell like him. That had to go, I had someone else to do it (079)."* On the other hand, the possessions that were representative to the memory, the specific events or the deceased were carefully stored (S2, S4, S5, S8, S10) and even used (S10).

#### 2. Manage the emotion (MA2)

The result suggested that both expressing and suppressing emotions were necessary and beneficial mechanisms depending on specific contexts or loss situations. Expressing emotions were considered natural and most comfortable when individuals were situated in a private and relaxing context such as home or bedroom. When individuals were at work or in public space, suppressing emotion was considered important to facilitate normal socializing and functioning.

The frequent emotion expressing behaviors were crying (all of the participants), talking to others (S2, S3, S7, S8, S10), showing anger (in the case of S5, she had a sudden rebellious period) or even blaming others (S1). Technology implementation was frequently observed in expressing emotions. Individuals utilized Skype, mobile devices or online forums to express their emotions to their other significant figures or online anonymous grievers.

On the other hand, 8 participants (S1, S2, S3, S4, S5, S7, S8, S10) explicitly indicated that their emotion expressing behavior would vary according to the context; *"when I was home, and I felt sad, I would cry. But when I was at work or with other people, I tried not to think about [my bereavement]. So it would not affect me (188)."* Managing emotion was regarded important ability to release emotional distress properly without letting the grief disturb the productivity.

In the case that technology contributed to help the participants to suppress emotions, S10 reported a conscious effort to keep a distance from people who try to comfort her by declining the calls; *"I just think [others] can't really understand...So I keep all these emotions only for myself, so I didn't answer the calls [from friends who tried to comfort me]. I only tried to work harder and I sometimes go for a long walk (096)."*

#### 3. Redirect attention (MA3)

Redirecting attention to the productive aspects of life could temporarily buffer the intrusive

distress and assist the participants to recalibrate life focus. Seven interviewees (S1, S3, S5, S8, S9, S10, S12) reported trying to withdraw attention from the loss and grief by exercising (S3, S10), working on new projects (S1, S3, S5, S8, S12), changing lifestyle (S5, S8, S10) and even changing the environment or the residency (S1, S10). Two good examples were S1, who left the familiar context to start a new life in a different country; *“I decided to go to Germany on purpose...that was a bit of escape or a new start in Germany. I changed like everything in my life, where I live, my friends...like everything. It was a risk, but I think it worked out (158);”* and S10, who buffered the stress by exercising; *“What I did is that I reduce the time working at the company and try to do something else. Not to forget him, but just to reduce the time thinking of him. I went boxing, I went Yoga and...I went running. I did anything (095).”*

Redirecting attention kept the bereaved open for the new opportunities or the other important social figures in the post-loss life. The bereaved could eventually develop new/deeper social relations or discover new focus of life.

#### 4. Nurture and comfort the self (MA4)

Making time to attend the individuals' physical or mental well-being were regarded beneficial for buffering the stress and preparing the bereaved for further confronting the grief. Some techniques observed in the self-nurturing process were meditating (S6, S8), listening to (S8) or making music (S11), and making time for self (S1).

We identified more products or applications being implemented to facilitate the self-nurturing processes, such as meditation apps, music players, instruments, exercise equipment, soft textiles or sports suits and self-growth books. Most of the self-nurturing behaviors were interwoven with the daily activities and were relatively light-hearted, but they could yield accumulative benefits for the long run.

#### 5. Continue and relocate the bonds with the deceased (MA5)

Seven interviewees (S1, S2, S3, S4, S5, S6, S12) reported continually thinking about, talking to and even inheriting some perspectives or attitudes from the deceased. S6 reported having a spiritual conversation with her deceased father; *[My father still plays an important role] in different ways...such as habits and values. Sometimes I tried to talk to him if I felt stuck in my life. [It was] not a talk, but more about what I think how my father would advise me and because I know him well so that I can answer myself (183).”* The emotional bond could be maintained even up to a decade after the loved one passed away. S2 exhibited strong miss to her deceased father; *“ [My father] died 14 years ago. And my father was a very very very important man in my life. That I say...I still miss him every day (005).”*

Besides possessing emotional and spiritual bonds with the deceased, some interviewees

also employed behaviors such as sharing stories about the deceased with other close figures (S2, S5), taking a trip back to the meaningful place regularly (S2), going through the meaningful possessions of the deceased (S3, S4) and having a conversation with the deceased when revisiting the grave (S4).

A unique discovery was that the bereaved not only communicated mentally to the deceased but also made explicit effort to pass on the stories, revisit the reminiscent places or inherit the perspectives or behaviors that represent the identity of the deceased.

#### 6. Meaning reconstruction (MA6)

Nine participants (S2, S3, S4, S5, S6, S7, S9, S11, S12) reported that they either found positive aspects from the experiences (S2, S3, S4, S6, S7, S11) or reinterpret the meaning of the bereavement (S4, S5, S6, S9, S12) during and after the bereavement process. The frequently identified strategies were writing (S2, S3, S6, S9, S10), talking to other supporting figures or psychological consultants (S2, S4, S5, S6, S11), going through the possessions related to the deceased (S2, S3, S5), recalling positive traits of the deceased (S2, S3, S4, S5, S6, S11) or making projects for the deceased (S2, S4, S5, S11).

Digital possessions, especially video clips, could be highly thought-provoking. Consider the example from S4; *“ [When watching the video about my father,] I was just reminded how much I loved him and how much he loved me. It was a nice feeling. His expression at that moment makes me feel relax. As I told you, it was a warm hello to me. I simply felt that he was telling me now in heaven. It was really strange (177).”* It did not suggest that S4 was not sad, but he had reappraised his perception of the videos.

#### 7. Seek support (MA7)

At least eight interviewees (S1, S2, S3, S4, S5, S8, S10, S12) reported the necessity to share their experiences, vent emotions, seek professional treatment or seek the company of others who were trustworthy and empathic. In deciding what resources to seek support from, four interviewees (S1, S2, S4, S5) decided to seek help from psychologists (S2, S4), psychiatrists (S1) or therapists (S5) for medical treatment, consultancy and psychotherapy and felt significantly supported. In addition to professional supporters, the other supporting figures were, but not necessarily, often partners (S3), close friends (S4, S8), family members (S1, S2, S4, S8) or other trusted elder figures such as supervisor (S12). Most of the interviewees believed physical interactions were important. For example, cuddling, face-to-face communication, conducting activities together such as eating, watching television or traveling together made the bereaved feel less alone and encouraged to engage in other meaningful relationships.

The support could also come from other anonymous resources (S5, S10). S10 went on the



internet forums to seek for experience sharing; *“I just go to [online forum] because there is a board called cat. All the people there have a cat. And some of their cats are dead also. So I posted some articles there and people said that “Yeah, I know what you are going through because my cat died (097).”*

The technology was frequently implemented in support seeking, such as searching for information or related stories, finding resources of treatments and mediating the relationship with the supportive figures. Furthermore, the bereaved often also experienced enhanced social relationship and self-competence after attempting to seek support.

#### 8. Perform rituals (MA8)

Three typical rituals were observed in the interview, to bid farewell, to mourn the deceased and to keep connecting with the deceased.

The first type is the ritual to say goodbye to the dying loved one. A proper farewell ritual often happened shortly before or during the dying process, such as staying next to the deceased or saying goodbye to the deceased before he/she passed away. S1 believed that staying with his mother before she passed away helped him to gain quality time; *“At the end [of my mom’s life] I was happy that I was there for the last six weeks...I think it was the quality of the time that matters rather than the amount of time (001).”* Sometimes when a proper farewell could not be fulfilled, the bereaved would do it again to “make up” the unfinished farewell gesture. In S4’s case, the loss came all of a sudden, and S4 still claimed the necessity to “do something physical” and to properly fulfill the farewell ritual; *“I went back to Colombia...because I was not able to say goodbye to my father. I visited him in his cemetery. I knew I had to do something physical...I had to talk to him, somehow, like saying hello and saying goodbye (022).”*

The second type was the ritual of mourning. The departure of the deceased was a process which could include mortuary, disposal of the body, and the funeral or memorial for mourning. Most of the mourning rituals were provided by professional service institutions or funeral companies but could be organized according to the will of the deceased. Funeral was also the most frequently reported ritual for paying respect to and mourning the deceased. In S2’s case, the dying loved one exhibited clear intention to be cremated instead of buried, and the wish was fulfilled respectively despite S2’s reluctance; *“One of my greatest depression was that my father wanted to be cremated and [we were to] just spread his ashes randomly, so I don’t have a place to go...and [my father’s] funeral was a very enclosed fair...we were only four people there because that’s also my father’s wishes...we needed to mark our [grief] (167 adapted from quotes in MA6 theme).”* Funeral was also the most frequently reported ritual for paying respect to and mourning the deceased.

The third type of ritual was to address the reminiscence and commemoration to the

deceased. S8 specified a traditional Chinese ritual of contributing virtual money to the deceased; *“After 100 days of my mom’s death, this was a tradition in [China], we burned the Joss paper (gold paper) to her...And even in the Netherlands, I printed the euro on the A4 paper and burned them to her. I told her not to save money, and enjoy her life [in the afterworld] (091).”* Although less seen in interviewees who belong to the western culture, there were also individual differences. S2 reported creating rituals to keep the memory alive; *“I think very much the need to keep his memory alive, so I created rituals. When it was 26th of November. We get his photograph, we light the candle, and we candle it every day until which is The 1st of December which was the day we were at his funeral (013).”*

As indicated by the result, performing rituals was associated with marking the mourning process and maintaining the emotional bonds with the deceased. Technology was not observed to be used frequently during this process.

#### 9. Create memorials or projects for the deceased (MA9)

In the assignment booklets, 9 participants (S2, S3, S5, S6, S8, S9, S10, S11, S12) mentioned creating diaries, poems, songs, photo collages, online articles, notes, rituals and even a project to reconstruct a house of the deceased. The intentions of making these mementos include: to keep the memory of the deceased (S2, S3, S5, S8, S12), to communicate to the deceased (S8, S9), to convey the stories and emotions (S3, S8, S11), to reprocess narrations of the bereavement (S6, S8) and to honor the deceased (S5). S2 and S5 reported atypical mementos. S2 had continued the ritual of memorizing the deceased for more than a decade, and she emphasized the importance to keep the memory of the deceased alive; *“By creating these rituals, I have tried to keep [my father’s] memory alive for me, my sister and his granddaughters. He deserves to be spoken about (answers in booklet S2).”* In S5’s case, the whole family has reunited again because of the house reconstruction project to honor the deceased; *“Now [our families] are back together. It took us more than ten years to patch things up. He’s more present than ever because we are building the house where he was born. That brings us all together quite a lot. Like a project after his passing but to honor him (129).”* Creating something for the deceased could also make the bereaved feel reconnected to the deceased (S7, S10); in S7’s example, *“by writing the article, I tried to express my emotion to [my mother], just like I can still talk to her, and she can still hear me (booklet S7).”* The quotes suggested that the “making” process was meaningful and sometimes therapeutical. Also to making tangible objects, two interviewees also reported personal changes such as engaging in new habits (S6) and new attitudes toward life and death (S6, S9). Although these two examples were less related to making tangible objects, they reflected the importance to commit effort in making personal changes.

The result indicated that individuals also engaged in other meaningful activities while

being inspired to make creation. For example, cognitive reappraisal, emotion reprocessing, continuing the bonds with the deceased, seeking social support and redirecting attention. Therefore, making something was considered a process of actively “working on” or “doing” the bereavement, and we believed it should be included in the meaningful activities. Technology played an important role that facilitated or enabled the crafting process.

#### 10. Conduct altruistic behaviors (MA10)

At least 8 participants (S1, S2, S3, S4, S5, S8, S10, S12) explicitly reported being more willing to support or exhibiting more empathy to other bereaving individuals due to their bereavement experiences. The typical altruistic behaviors included spontaneously sharing experiences (S4, S5), giving gifts (S12), making donations (S10) and accompanying or physically taking care of the bereaved (S1, S2, S3, S4, S8). For example, S10 mentioned donating money to cat shelter could comfort her; *“by donating some money to the cat shelter in Taiwan. Just to make me feel comfortable (199).”* Sometimes the target for altruism was not limited to the bereaved. S12 had a realization that her kindness could be valuable for people who were in need; *“I realized that my caring words or little gifts could be helpful for others. Because others would feel very valued. I believe my kindness can still be meaningful to others (105).”*

Another approach to conducting altruistic behavior was to pay attention to the other surviving important figures (S1, S2, S4, S6, S8, S11). S4 reported paying more attention to his mother after his father passed away; *“Now [my mom is] the spoiled girl. We really care for her. At least for me, it was a good strategy to redirect my attention from my father to my mother. Now I put all my energy, my effort, my interest and my concern, all I wanted to do on my mom (024).”* Others also reported redirecting attention to other family members, partners or close friends.

The result proved that altruism was very frequently observed and was potentially helpful for the bereaved’ mental comfort and self-growth.

#### 11. Denial and avoidance (MA11)

Denial and avoidance allowed the bereaved a certain period of buffering and escape from the stress of confronting grief. Six participants (S1, S3, S5, S7, S9, S11) reported consciously making an effort to avoid being reminded or thinking about the bereavement experience. Typical activities include to avoid reminiscent places (S1, S3, S5) and reminders (S7), to refuse to talk about or to pay attention to the bereavement (S7, S11), and to pretend nothing happened (S3, S9). S7 consciously avoided placing reminders in the working space so she would not be reminded of the bereavement experience; *“I think not having pictures that remind you [of the loss] is easier. For example, at work, my desk was simple. It doesn’t have many personal things, [so I won’t be reminded] (189).”* However, avoidance could hamper the

coping and reprocessing of grief, and S5 mentioned feeling a bit depressed after avoidance; *“I was very angry [at everybody]. It’s not a necessary coping strategy, but it’s like trying to hide the [grief]...trying to avoid coping with them. Avoid [accepting the grief]...after that, I was in a bit of depression (181).”* As other literature suggested, we also believed that denial and avoidance had a protective effect at the early stage of the bereavement experience. However, it was worth to note that avoidance was meant to prepare the bereaved for confronting the grief and should not be adopted as a long-term bereavement activity. There were no examples of denial and avoidance mediated by technology.

### 3.5.2 Positive outcomes (PO)

Our result also demonstrated the potential positive implications of the above-mentioned activities on the griever’s post-loss psychological well-being. Ten (S1, S2, S3, S4, S5, S6, S7, S8, S11, S12), out of the 12 interviewees, reported experiencing post-loss positive changes on at least one dimension of psychological well-being. Three of them even reported experiencing positive changes on 3 dimensions of psychological well-being (S2, S5, S6), showing that positive changes in psychological well-being were not absent in the bereavement processes.

#### 1. Personal growth (PO1)

Although many interviewees experienced personal growth, it did not suggest that it was a taken-for-granted outcome of bereavement but required significant effort to achieve a certain level of personal maturity and resiliency. Some meaningful activities that exhibited strong potential to lead to personal growth were managing emotions (MA2), meaning reconstruction (MA6), creating mementos or projects for the deceased (MA9) and conducting altruistic behavior (MA10).

Half of the participants (S1, S2, S5, S6, S11, S12) reported feeling more self-confident (S1, S6, S11), more resilient (S12), mentally stronger (S1, S6), more empathic (S2, S11), mature (S1, S5) and enhanced spirituality and identity (S1, S5). The result also showed that actively experiencing and processing the bereavement and grief allowed individuals to achieve emotional and cognitive development. This positive change could then lead to long-term influence such as enhanced resiliency (S12); *“I think after several types of losses, my mind become more resilient. I become more tolerable to future disasters (207).”* Besides the positive growth at the individual level, personal growth even evidenced potential impact at the social level. S2 claimed to be more empathic than before suffering the bereavement; *“what did I learn from the grief process...not necessarily stronger but more empathy for others [who also suffered from bereavement] (067).”*

#### 2. Self-acceptance (PO2)

The activities that could best facilitate acceptance were making sense of the bereavement (MA4), meaning reconstruction (MA6) and performing funerals or farewell rituals (MA8). Four participants (S2, S3, S4, S6) reported being able to accept the reality as what it is and that the self should try to see the positive side of it. S2 mentioned that she was able to come to the self-realization that life could be tough, but one still could enjoy it; *“There are the life lessons as that...you don’t control it where you wanted...when things get tough, enjoy life. That’s what [the deceased] did (066).”* Another example was from S3; *“[Death of loved one] is something that I couldn’t control. You don’t know when the final destiny of a person is. It’s hard to estimate. So I don’t feel sorry for my grandpa (018).”* Although accepting the result seemed relatively passive, the interviewees still committed great effort in finding positive aspects or looking at the positive sides of the reality, which finally made the bereavement acceptable. Consider the example from S4; *“You always have to look at the positive side and I am constantly doing it now. And also when [my dad] passed away, he would also want me to look at the positive side of it (021).”* We also observed behaviors of saying goodbye to the dying loved ones, which made it easier to accept the death. S3 reported visiting her grandfather before he passed away and was mentally prepared for the death; *“When I visited him 3 months before he died, he cried. This was the first time I saw his tears...I felt that [his last] day would come and it would] not be far (170).”* Enhanced self-acceptance was therefore considered one of the positive changes because it cultivated the bereaved’ positive appraisal towards the loss experiences and acknowledgment of the various aspects of self and life.

### 3. Autonomy (PO3)

Our interviewees reported being more self-responsible for the lifestyle or health (S6, S7) and reprioritizing personal values and behaviors without conceding to social pressure. S12 reprioritized her time management for important figures; *“although losing a figure is painful, it reminds you what are important things in your life, the importance of [spending time for] your close figures (209).”* A similar example could be seen from S6; *“now I do meditate much more and I feel much more engaged. I also try to be more careful the way I spend my time. I care for instance really making time for friends or family. And do more sports, things like that. Things for health reasons or a resilience life (032 from Uncategorized cards).”*

The result suggested that individuals gained higher mastery on themselves by reprioritizing life focus (MA3) nurturing their mental health (MA4), changing their thinking style (MA6), and caring for others (MA10).

### 4. Positive relations with others (PO4)

The most frequently observed positive change was on the solidified relations with other important figures such as family members, friends, partners or other significant others. Seven

Participants (S1, S2, S4, S5, S6, S7, S8) reported having more positive relations with other important figures or reprioritizing relationships with others (S1, S6). Some participants chose to pay more attention to surviving family members or friends after experiencing the death of the loved ones. For example, S8 tried to talk more with her father after losing her mother; *“My father is a reticent person, so we usually don’t talk a lot...so I tried to talk more with him now. He is lonely [after my mom passed away], I understand (089).”* S6 claimed that the loss experience reconfigured her relationship with almost all her friends but still regarded it a positive thing since she could differentiate the important connections; *“the passing away of my father reconfigure my friendship. Some friendships grew stronger and some weaker (085).”*

It is worth noting that according to our result, having positive relations with others could be both a positive change and a resource for coping with the bereavement experience. People who had more close supporting figures experienced social relationship as a buffering resource that protects them from being overwhelmed by the radical life changes. Seeking support from other figures (MA7), sharing stories with common friends or family member (MA7), performing memorial for the deceased together (MA8), supporting other bereaved people (MA10), and even expressing emotions to attract help (MA2) were often observed in our interview as activities that lead to more empathic and enhanced social relationships.

Another way of having a positive relation was the positive attitude towards and spiritual connection with the deceased loved ones (check result of continue and relocate bonds with the deceased (MA5), S1, S2, S3, S4, S5, S6, S12). The inherited lessons, stories, personalities, preferences or habits from the deceased had posted significant and residual effect on the bereaved. Having a positive relation with the deceased, spiritually or ritually, enriched the bereaved’ post-loss lives and pacified their pain thinking that deceased no longer existed in the world.

### 3.5.2 External support (ES)

Bereavement was a long journey, but not necessarily a lonely one. In the previous section of meaningful activities, the participants indicated that support seeking behavior helped them to gather emotional or tangible support from their social community and benefitted their coping with bereavement. The result from this study suggested that supporting the grievors was not necessarily a unilateral process. Sometimes the external resources from the social community would be available without grievors’ support seeking initiative, and these types of spontaneous support could be equally or more appreciated. Six participants (S2, S4, S6, S7, S8, S11) reported almost 12 times of being spontaneously supported by their organizations (S2), friends (S4, S6, S7, S8), family members (S2, S4), partners (S7, S11). S2’s case was worth considering; *“the university*

*also gave me already at that time, gave me time off work, no questions asked. My boss was amazing. "Go, sort it. We'll talk about it when you come back. Don't even think about [work]." So [that was a] tangible support (165).*" It showed that the support from work organization could be helpful to reduce bereaved individuals' stress of having to spend time on work during bereavement.

There were a variety of forms for external support, ranging from making telephone calls to taking care of the bereaved in many aspects of their lives. Here we provide some examples. In S4's case, his friends played a critical role to share his burdens; *"My friends here took care of me [after my father died], arranging [flight] tickets, talking, and they took over my position [in the project] while I was abroad. The support from them was amazing. And without that, the coping would be really hard (075).*" Other examples included being more sensitive about the bereaved' life changes (S6), making a lot of phone calls (S2), cooking (S8) for the bereaved and encouraging the bereaved to express emotions (S11).

## 3.6 Discussion

### 3.6.1 Comparing with preceding studies

#### Bereavement psychology

Most of the activities extracted by the explorative study can also be identical to the activities identified from psychological literature (see the brief review in section 3.2). The activities identified in the result and are identical to the activities from the review are managing emotions (expressive flexibility) [113, 138, 139], denial and avoidance [145, 146], seek support [55, 59, 147, 151, 188-190], continue and relocate bonds with the deceased [90, 158, 191, 192] and meaning reconstruction (make sense, find benefit and reconstruct identity) [41, 43, 193]. The other activities that were less explicitly discussed in the psychological literature are dealing with memorable possessions, nurturing and comforting self, redirecting attention, performing rituals, creating mementos or projects for the deceased and conducting altruistic behaviors.

Although six activities were not listed in our literature review, it does not mean that these activities are only discovered from this study. These activities were frequently discussed in fields such as thanatology or psychotherapy (e.g., meaning-oriented psychotherapy). They are more related to an individuals' needs of memorizing and honoring the deceased rather than directly connected to regulating emotional distress or cognitive appraisal. Identifying these activities and how they were often conducted with or without technology can contribute to exploring the possible needs that are currently mediated or can be fulfilled by technology. The designers can further explore the design opportunities with insights translated from the different fields.

#### Thanatosensitive technology and social death

We have identified several similar activities that are related to the findings of previous research, which significantly proved that technology is exerting an increasing influence on our dying and mourning experiences. For example, managing digital possessions have been elaborated in several papers [11-13, 194-196], which could be stressed on organizing and bequeathing meaningful digital possessions, relating to the digital remains and making meaning of the devices or the digital legacy related to the deceased. Continuing and relocating the relationship with the deceased was also seen in papers of Walter et al., Getty, Massimi and Odom et al. [1, 19, 197]. Digital memorials and live stream funerals are existing services and are elaborated in many papers [62, 198]. Social support for the bereaved or even for the disenfranchised bereaved groups was also discussed in Walter et al. and Massimi's publications [1, 2, 199]. However, some of the activities (e.g., nurturing and comforting self, conducting altruistic behavior and denial and avoidance) identified in this study were less discussed in previous literature and the knowledge of how to enable them through PSS remained scarce. It proves that designing for end of life span is a growing field in HCI, and more studies would help to inform the field about how to better attend the needs of the dying and the bereaved.

### 3.6.2 The role technology plays in the coping process

Although more than half (51.7%) of the world population is on the internet in 2017 [200], the bereaved internet users are no different to the normal griever in conducting the activities to cope with grief, and many activities identified in the study did not necessarily require technology (such as avoidance and denial). The majority of activities identified in our study mostly involved personal devices, social network, and internet. Our participants often used the internet to seek support, find information, read other griever's stories and share their own grieving stories. The role technology plays in the bereavement process is a mediator that empower the decision-making process and enable the coping activities. The two design opportunities are designing to empower and to enable. Below we elaborate the two opportunities with more details.

#### Design for empowering decision-making

Based on the result, decision-making is critical towards a positive bereavement outcome. The bereaved encounter a myriad of situations that they should make decisions, and their decisions could directly or indirectly influence the outcome of the bereavement. Technology was observed to be frequently utilized in mediating the access to information or supportive resources, which assisted the griever to acquire guidance and make the coping-related decisions.

For the coping-related decision-making, the participants indicated that they did not



know what to do at the beginning of the bereavement period. Death of a loved one assumes a major life change for the bereaved. Besides adapting to the life and meaning changes, the bereaved also face challenges from mortuary, law, economy, custom or society, all of which seem disorienting and overwhelming. The result indicated that the bereaved often felt stressful having to deal with much more other issues in addition to the emotional distress.

Another context is in making the end of life decisions related to the loved ones (before the death). Although the study mainly concentrated on what activities the participants conducted after the loved ones died, we noticed that the bereavement process could start before the death took place. There were two cases that the decisions made before or during the dying process severely saddened the bereaved could significantly hamper their post-loss well-being. One of the interviewees (S8) suffered from strong regret and pain because she decided to go back to work in another country but missed the chance to accompany her mother before she passed away. Another example was S2, who decided to sign the DNR for her suicided father but experienced strong anger to her father. These decisions were difficult to make, and sometimes the consequences were hard to estimate. To know in advance what decision would lead to a satisfactory outcome is almost impossible, which is perhaps like saying if one can see the future, one would never have regret or make mistakes. However, through learning from others experiences and the potential consequences of the activities, the bereaved could be empowered to make the confident decision and be prepared for the potential consequence.

Decision-making during and after death of a loved one is surely critical because, in many cases, the decision had to be made quickly or without previous knowledge about the consequences. Sometimes the other close figures (family members or friends) were also in agony to provide proper support in the griever's decision-making process. This particular issue is an opportunity for intervention, not necessarily for technology designers only, but can serve as an inspiration for designing to support the bereaved. What decision to make, and what consequence(s) could arise from the decision are two important questions designers should bear in mind. In addition, the decision should be made in the early phase of bereavement since it could enable the bereaved to manage and regain autonomy in their post-loss lives.

Design for enabling meaningful activities

Following the discussion in the designing for empowerment, technology was also frequently implemented in facilitating the activities such as organizing the digital possessions of the deceased, creating music or online album for the deceased, sharing the stories of coping in a forum and contacting supportive friends from a distant land. There are various examples of technology-enabled/mediated activities identified in the study, most of which involve internet connection, suggesting that staying connected can be an important consideration for the

technology design.

Activities are often goal-oriented. Most of the coping activities reported by the interviewees were conducted not only to regulate the distress, but also to maintain a normal social life and work productivity. Conducting activities to cope with grief implies that the bereaved believe that the activities conducted could contribute to the positive outcome of bereavement. However, not all activities would lead to positive outcomes. For instance, the result has indicated that some of the participants regretted conducting a certain behavior to cope with their losses (such as behaving rebelliously to vent the anger or blame another family member for the loss). Learning from other people's experiences, professional guidance or other resources of story sharing could support the griever in understanding what activities to take to cope with their grief.

The proportion of activities enabled by technology is not very high but in some of the activities such as organizing digital possessions, for which a computer and a hard drive are inextricable, or posting personal story anonymously on the internet, which can only be enabled by operating a device connected to the internet. As a result shows, since technology has been increasingly interwoven in our everyday life experiences, more and more human activities would involve technology and internet. Even though the result did not support the statement that technology plays a major role in our bereavement coping process, it did support the statement that technology has a strong potential to facilitate our bereavement coping process by enabling the activities that could contribute to positive coping outcome.

## 3.7 Limitations and Conclusion

### 3.7.1 Limitations

The nature of the study is highly explorative, and there was a limitation of the convenience sampling method. Most of the participants, being internet users and willing to share grieving experiences with us, recruited from the convenience sampling appeared to be higher-educated and from higher socio-economic class. There were also more female participants than male.

Another limitation lies in the possibilities of including various types of technology. It has to do with the study objective. This study selects coping-related activity as the major target to investigate and explore design opportunities within the process. Although the saturation is checked based on the types of activities uncovered from the study, the types of technology involved in supporting the activities could be more diversified. For instance, streaming funeral on the internet can be an example of conducting the ritual, but none of the participants

reported this technological intervention. More studies are required to understand the types of technology that can be implemented in the bereavement process.

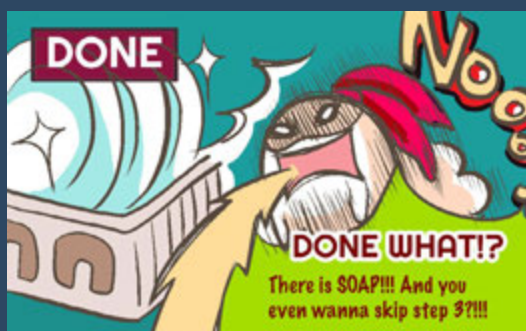
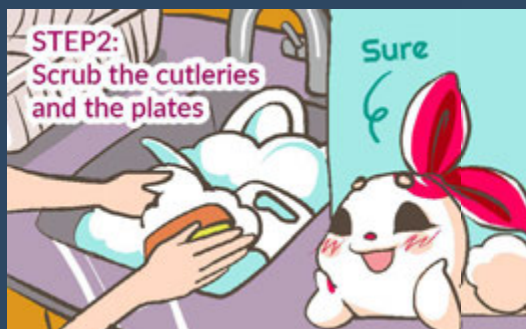
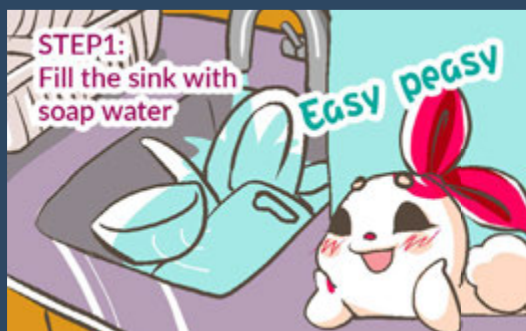
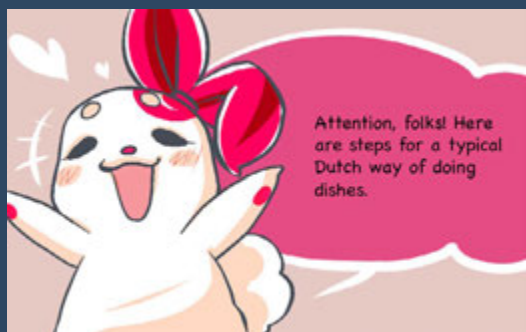
### 3.7.2 Conclusion

In this chapter, we presented an explorative study that identified eleven meaningful activities that can contribute to positive bereavement outcomes and discussed the design opportunities according to the coping process. The two major types of design opportunities are designing for empowering the decision-making and designing for enabling the meaningful activities. Focusing on the activities allows designers and researchers to understand the goal and impact of the activity. The design opportunities extracted from the study are not limited to uncovering the current interaction with technology but more related to identifying the needs that should be facilitated during the bereavement process. In comparison to previous studies that concentrated on the existing patterns of interacting with technology [2, 3, 131, 195-197, 201], this chapter offers an activity-oriented perspective to imagine the technology that is not yet existed or the possible interaction that has not been created.

Technology has yielded growing influences on our health and well-being. With that being said, studies that consider how to support individuals in the critical and challenging life conditions through technology are just emerging. It is obvious that more studies are required to delineate the approach to design technologies that enable and mediate these activities. Furthermore, it is also critical to gain deeper insights on how to empower the griever in making the personally meaningful decision and what activities need to be enabled to support the decision. Coping with the death of a loved one does not have to be a destructive event but a profound life experience, and technology, with its potential to mediate meaningful activities, can certainly play a positive role in this life-changing event.

# WASH DISHES

One of the problems is that our tolerance of soap residue on dishes are so distinctively different



Dutch tip:  
This way saves water, and soap is **EDIBLE**.



Originally published in Oranje Express

Sep 10, 2015

## Chapter 4 The Development of a Monitoring and Feedback System for Predicting Poor Adjustment to Grief

### 4.1 Introduction

Self-management is often considered one of the critical factors that contribute to promoting a better medical or mental healthcare outcome [202-209]. 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 [210]. 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 healthcare processes and more faithful in following the therapy instructions [211, 212]. The advantage of utilizing self-managing applications in the medical and psychological care procedures is that these applications are more accessible and integrated into users' everyday life experiences. They are often characterized by low cost, connectivity, anonymity, non-stop availability, and opportunities for a self-paced healthcare approach (see the introduction of mHealth by Free et al., 2013). For healthcare 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.

As presented in Chapter 3, the technology involved in the bereavement-related activities are often personal devices (such as the computer or mobile devices) that can be connected to the internet. 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 [55-57]. However, as Krysinaka 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 [58].

Accordingly, this chapter takes a focus on designing an internet-based data gathering system that can be implemented in building the screening (predictive) algorithm and facilitates a better understanding of users' interaction experiences. The next section introduces the context of usage, especially regarding the tension between the minimum required period for diagnosis and the time point that the clinical intervention could be mostly needed. Two approaches to building the data gathering system are motivated based on reviewing the relevant literature, My Grief Journal and Grief Inquiries Following Tragedy (GIFT). GIFT is selected for further predictive algorithm validation and user experiences evaluation.

In the end, this chapter reports a preliminary user experiences evaluation of GIFT and elaborate its potential to serve as both a data collection instrument in the future studies and a prototype for self-monitoring system in the bereavement process.

### 4.2 Context of Usage-Bereavement

Bereavement refers to an individual's adaptive process following the loss of a loved one through death [32, 92, 93]. 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 [49, 74, 213]. It is also a fundamental and life-changing event that almost everyone will encounter in their lifetime. The prevalence and ubiquity of loss and grief is 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 [26].

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 [32-34, 36, 106]. 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 [38, 39, 43, 88]. However, the prevalence of adult grievers who could develop PGD is also noteworthy (9.8%) [51]. In the paper published by Maercker et al. (2002), they even pointed out that the conditional percentage could range as high as one-third of the grievers could suffer



from PGD (p.171).

For the individuals who suffer from PGD, psychotherapeutic intervention is most needed to support their adaptation and acceptance of the loss. On the other hand, performing grief counseling and therapy to normal grieverers could yield deleterious effect and even disturb the natural bereavement procedure [45-47, 214].

Since the effect of offering grief counseling to normal grieverers is unwarranted, a screening method that helps to determine who will benefit from the psychotherapeutic intervention is of the primary importance. Our previous discussions (see Chapter 2 for a more extensive literature review) have outlined the importance and pressing need of a reliable screening method, whereas the current PGD diagnosis instruments require a minimum six 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 grieverers 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 six months have elapsed. It could potentially explain why studies related to preventing PGD remained scarce and the effect far from warranted.

### 4.3 Two Approaches to Predict PGD symptoms in Early Phase

Assessing symptomatology and attending to the needs of grieverers 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. In this section, we selected the studies that attempted to predict grief severity based on investigating the grieverers' activities and situations in the context to build the understanding of what kinds of data should be gathered and are informative to the development of PGD screening algorithm.

The first group stems from the problematic narratives and coping strategies that can potentially be detected through linguistic cues [167, 170, 215, 216]. Examples of the first approach include negative self-evaluation such as thinking that the self is less worthy without the deceased [167], and problematic coping strategies such as repetitive rumination of the deceased [170]. 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 be moderated by psychotherapy in the early phase of

bereavement [128, 129, 189, 190, 217-221]. Examples of the second approach range from traumatic death [218], lacking social support [35, 55] to the strong dependency on the deceased [35, 222] and an insecure attachment style [223-226].

Both approaches are informative for follow-up development of screening algorithms because they indicate what types of data should be gathered (the linguistic cues among grieverers' self-evaluation and the risk factors that the grieverers are exposed to) to monitor the bereaved's susceptibility to PGD and to target the appropriate interventions in a more timely manner. The next section reports the technology used to develop the two prototypes and examine the feasibility of these two prototypes and select one for further data gathering and user experiences evaluation.

## 4.4 Method

### 4.4.1 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 developed based on the available technological solutions and studying the related bereavement literature. The second prototype, Grief Inquiries Following Tragedy (GIFT), was developed with field experts and psychotherapists. The overall aim of both applications is to gather the necessary data and users experiences feedback that can be used to build the predictive algorithm in the final research deliverable. 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 six months ago.
- Deliverable: an Internet-based PSS that can serve the data gathering purpose for critical predictive variables that help to build the predictive algorithm of PGD.
- Portal: the application should be affordable, easy-to-use, and widely accessible through the computer and mobile devices.
- Data to be gathered: The system must collect critical bereavement-related data from the users, and generate personalized feedback based on the data collected to understand users experiences on this type of self-monitoring.
- Ethics: The feedback provided to the users in the prototypes, despite the highly explorative nature of the study, must contain both positive and negative aspects of

their grief situation and must come from the authentic sources.

- Scalability: The prototypes should attempt to integrate and utilize the existing and validated technology (or psychological scales) as a starting point but should remain flexibility for developing and validating new measures.

#### 4.4.2 External experts from the bereavement and psychotherapy field

Although the purpose of this project was not to develop an intervention of PGD, due to the sensitive nature of loss and grief study, we invited one researcher specified on bereavement and post-loss meaning reconstruction and one psychotherapist specified on grief counselling. The external experts mainly contributed to the design and phrasing of questions that were used in assessing the griever's grief experiences and provided further opinions from psychological field on the ethics and design of the study. We first proposed two prototype concepts based on 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 Institutional Review Board (IRB), to pilot test the app and gain users feedback from the concept, we had recruited a certified thanatologist and grief counsellor 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 researchers and the psychotherapist to ensure the questions would not steer dangerous emotional responses. The interview was conducted in English and all of the users were native English speakers.

#### 4.4.3 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 studies endorsed that verbal materials carry more additional information about psychological phenomena and symptoms, which are often less detectable from self-report [216, 227]. 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.

We 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) [228]. 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 [229], Afinn [230], and IBM AlchemyAPI [231]. 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 were 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. In addition, although the word counts gave an indication of the degree of positive/negative emotions, it could not clearly differentiate whether the positive/negative emotions were pointing towards the event, deceased, life challenges or other context. How to nudge users to regularly write the journal can also be a foreseeable challenge.

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 5 types of emotions (anger, disgust, fear, joy and sadness). Figure 4.1 and 4.2 showed the sample page and report of My Grief Journal.

#### 4.4.4 Grief Inquiries Following Tragedy (GIFT)

In comparison to My Grief Journal, extracting information from validated measurement and providing bereavement-related feedback seemed relatively straightforward and more widely accepted in psychology. The concept of GIFT stemmed from psychological studies related to prospective risk factors that could render griever's more vulnerable to PGD, such as low social support [232, 233], or close kinship with the deceased [137, 234, 235]. Table 4.1 presents six confirmed risk factors suggested by the literature. The original concept to measure the risk factors was a checklist of risk factors, and the more items confirmed "agree" in the checklist indicated the higher vulnerability of the participants to developing PGD. We also included a selection of potential risk factors based on the 32 potential risk factors presented in the review paper of Burke and Neimeyer (2013). These potential risk factors in combination with the confirmed risk factors were categorized into the following groups: background factors (including socio-demographic information and information of the deceased), bereavement risk factors (including



Figure 4.1 The entry page of My Grief Journal



Figure 4.2 The demo visualization of keywords and the valence of the keywords

interpersonal, intrapersonal and illness/death-related factors), and bereavement outcome factors. This categorization took reference from the categories and frameworks presented in previous studies that examine the relationship between different predictive/risk factors [128, 129, 236]. The complete list is presented in Table 4.2.

All of the risk factors were reviewed by the researchers and the external experts. Two measurement tools were designed to measure the risk factors. We have further included another to-be-validated scale for identifying risk factors related to bereavement and loss circumstances, Bereavement Risk Inventory and Screening Questionnaire (BRISQ) [236]. These three questionnaires were grouped into the major section, Basic Information, to gather the data of most of the risk factors. Basic Information consisted of questionnaires related to the participant's background factors and proposed bereavement risk factors (Table 4.1; scales #1-3). Six validated questionnaires were selected to provide feedback on bereavement-related outcomes to fulfill the ethical consideration and to gather more data on the outcome predictors. The five questionnaires (except PG-13 which evaluates PGD) were selected because the psychological states or disorders measured by these questionnaires were hypothesized to be highly related with PGD. We included three measures related to negative bereavement outcome and three questionnaires related to positive bereavement outcome. They measured respectively PGD diagnosis (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 titled Monitor My Grief. Table 4.3 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.

We decided not to provide personalized feedback based on Basic Information because the effective predictive algorithm is yet to be developed based on the data gathered, but feedback was drafted for the 6 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. In the end, all the feedback will be compiled into a personal report that can be sent to them and shared with their friends. The details of each questionnaire were described below.

Table 4.1 Confirmed risk factors suggested in review papers [128, 218]

Confirmed risk factors	Details
Social support level	Lacking social support is a salient risk factor that is highly related to problematic grief [35, 55]
Attachment style	Avoidant/anxious/insecure attachment style is considered the cause of difficulty to adjust to loss [223-226]
Discovering the body	Discovering the body or viewing the death scene (especially with traumatic nature) is a salient risk factor for PGD [237]
Close kinship	Being a spouse or a parent of the deceased, or having close kinship with the deceased are significant predictor of PGD [137, 234, 235]
Pre-death dependency	High levels of pre-death marital dependency is a primary risk factor [35, 222]
Neuroticism	History of mental illness is a strong predictor [56, 225]

Table 4.2 Groups of variables

Group	Independent variables
Background factors (n = 12)	Socio-demographic factors of the bereaved: being female, the bereaved age being young, close kinship (being a spouse or a parent of the deceased), low education, frequency of religious activities, importance of faith, multiple prior losses Factors related to the deceased: recency of death, violent death, pre-loss frequency of contact, deceased's gender opposite of bereaved, younger age of deceased
Bereavement risk factors (n = 25)	Intrapersonal factors: neuroticism, history of mental illness, belief in therapy, negative interpretation of grief, lack of religion/spirituality, limited existential worldview, low income Interpersonal factors: lack of closeness with the deceased, high dependency to the deceased before death, problematic relationship with the deceased, unresolved regret to the deceased, caregiver burden, low social support, insecure attachment style, poor family dynamics, low technology use, others are frequently concerned about how the bereaved is grieving Situational factors: suddenness of death, perceived preventability, multiple concurrent losses / traumatic events, difficulty reconstructing meaning post-loss, lengthy illness, perceived unpreparedness of the death, discovering the body, perceived suffering
Bereavement outcome factors (n = 5)	Posttraumatic Stress Disorder Major Depressive Disorder Resilience Integration of Stressful Life Experiences Posttraumatic Growth

1. Personal Information

The personal information questionnaire was developed based on several hypothesized sociodemographic risk factors and the information about the deceased: gender, age, relation to the deceased (spouse or parent), marital status, employment status (financial burden), importance of religion or spirituality, young age of the deceased, type of death (violent death), other losses in the past three years, the duration of knowing the deceased and the frequency of contact with the deceased prior to the death (see ). These information helped researchers to gain a thorough understanding of the loss circumstances and validate if these hypothesized risk factors contribute to predicting PGD.

2. Complicated Grief Risk Factors Checklist (CGRF)

This study sought to evaluate around 25 bereavement risk factors. Each of the CGRF question corresponded to a specific risk factor and the questionnaire comprised of 25 questions. Five risk factors were derived from the confirmed predictors: neuroticism, pre-death high dependency, low social support, insecure attachment style and witnessing the death scene / viewing the dead body. Other factors were derived from review papers and clinical practice. The questionnaire was a work-in-progress measurement co-developed by the researchers and the psychotherapy experts specified in bereavement research and treatment.

3. Bereavement Risk Inventory and Screening Questionnaire (BRISQ)

The Bereavement Risk Inventory and Screening Questionnaire (BRISQ) is a self-report screening tool developed primarily for cancer loss [236]. It contains two versions for pre-loss and post-loss screening. The study reported in this thesis adopted a cross-sectional data collection approach, hence we used the post-loss version of BRISQ. The questionnaire was acquired from the Memorial Sloan Kettering Cancer Center.

4. Prolonged Grief (PG-13)

PG-13 is a robust diagnostic tool of Prolonged Grief Disorder (PGD in short, equivalent to PGD in DSM-V) which is widely used in studies related to PGD [49]. It was comprised of five criteria adherent to the criteria stated in DSM-V. In order to confirm PGD, the bereaved must meet all five criteria: encountering a death of a loved one, having severe separation distress, duration of loss longer than 6 months, experiencing other cognitive, emotional or behavioral symptoms to a chronic level, and having significant impairment in social, occupational or other aspects of functioning. The study employed the criteria of PG-13 to determine the membership of normal grievers or PGD grievers. PG-13 can be acquired through contacting the researchers who developed measurement for PGD.

5. PTSD CheckList – Civilian Version (PCL-C)



For measuring Posttraumatic Stress Disorder (PTSD), we selected PCL-C, which is a widely adapted self-administered scale for PTSD [238]. It comprises 17-items that measure the symptoms of PTSD defined by the American Psychiatric Association’ Diagnostic and Statistical Manual (DSM-V). Researchers can find various versions of PCL on the website of US Department of Veterans Affairs and also employ the version and suggestive cut point that they find best fits the study purpose.

6. *The Center for Epidemiologic Studies Depression Scale Revised (CESD-R)*

CESD-R is a 20-item screening instrument measuring depression and depressive disorder based on the criteria defined by DSM-V [239]. The result consists of five categories ranging from Major Depressive Disorder to no clinical significance. The complete questionnaire can be accessed from the center of epidemiologic studies website and is free of charge.

7. *The Connor-Davidson Resilience Scale 10 item (CD-RISC-10)*

Resilience is defined as one’s ability to regain emotional equilibrium after experiencing a potentially traumatic event. Individuals with higher resilience are believed to be able to adjust better when encountering stressful life challenges. Connor-Davidson Resilience Scale is developed to measure an individual’s resilience and has three versions: the 25-item, 10-item, and 2-item version [240]. Researchers need to purchase the questionnaire from the developer to be authorized to use the questionnaire in the study. The 10-item scale was selected for this study due to the concern that 25-item scale might cause an overload for the participants in the process of filling all the questionnaires.

8. *Integration of Stressful Life Experiences Scale Short Form (ISLES-SF)*

Meaning making was hypothesized to be the crucial mechanism that facilitates the adjustment to a stressful life event [241]. ISLES-SF consists of six items and has been validated to perform well in measuring the meaning making ability after an individual experienced loss of a loved one. The item 1, 2 and 3 of ISLES-SF measure the comprehensibility of the event and the item 4, 5 and 6 measure one’s sense of having a footing in the world after the stressful life event. The questionnaire is free accessible on the internet with multilingual versions available.

9. *Post-Traumatic Growth Inventory (PTGI)*

Experiencing posttraumatic growth following the trauma is not a rare phenomenon. The types of growth are well documented and can be measured through PTGI, a 21-item scale to measure positive outcomes following the experience of trauma. The types of posttraumatic are divided into five factors: New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life [37].

*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 4.6 for an example). The handle will change color after an answer has been indicated (see Figure 4.7 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 4.8).

*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 4.9). 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.

Table 4.3 Assessment instruments

Scale Set	Scale Name	To Assess
Basic Information (including loss related characteristics)	1. Personal Information	Demographic data, such as age, gender, ethnicity, religious affiliation and information related to the deceased
	2. Complicated Grief Risk Factors Checklist (CGRF)	Proposed predictors of bereavement distress
	3. Bereavement Risk Inventory and Screening Questionnaire (for the bereaved; BRISQ-B) [236]	Risk factors of Prolonged Grief
Monitor My Grief	4. PG-13 [49]	Grief severity
	5. PCL [238]	Posttraumatic Stress Disorder
	6. CESD-R [239]	Major Depressive Disorder
	7. CD-RISC-10 [240]	Resilience
	8. ISLES-SF [241]	The ability to reconstruct meaning post-loss
	9. PTGI [37]	Posttraumatic growth
NOTE: Scales #1-3 assess bereavement risk factors. Scales #4-9 have been empirically validated and are widely used in bereavement research.		

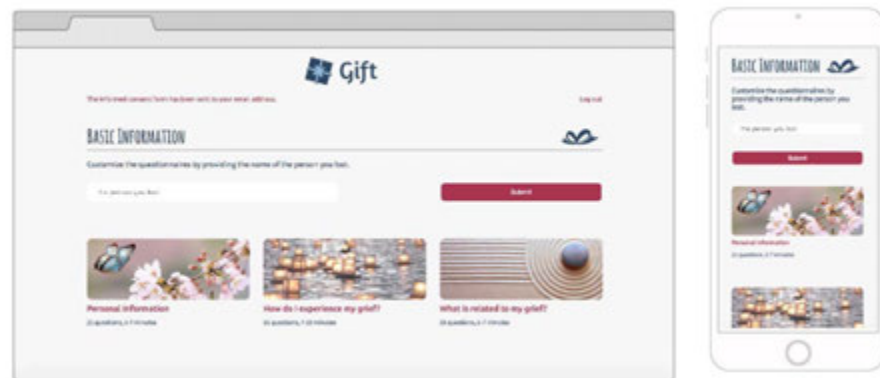


Figure 4.3 GIFT entry page



Figure 4.4 GIFT slider scale



Figure 4.5 GIFT feedback



Figure 4.6 A slider for Likert Scale answer



Figure 4.7 Slider response after an answer is indicated



Figure 4.8 The responsive slider on a mobile device



Figure 4.9 When user selects "N/A," it means that the statement could not apply to his/her situation

#### 4.4.5 The evaluation of both apps and the pilot test 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 before the six month threshold of diagnosing PGD.

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 (IRB) from both United States and the Netherlands, in which the former is where the study will be conducted and the later where the app was conceptualized and developed.

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 counselling 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).

### 4.5 Result

The protocol analysis sessions for GIFT pilot testing were all audio recorded and completely transcribed. Each session was approximately one and half 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 griever. Their socio-demographic data is displayed in Table 4.4. Almost all of the participants bereaved about the loss of a family member. 80% of them 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 six months ago, the other participants generally experienced death of a loved one for more than six 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.

We asked the participants to evaluate the relevancy of the questionnaires and help to provide feedback on the phrasing and the options design of the questionnaires. Both BRISQ and CGRF were considered particularly relevant to the majority of participants. BRISQ was more frequently considered thought provoking and meaningful. However, PA3 indicated that BRISQ could affect the users in a positive or negative way since it contained a lot of triggering questions. Personal information was considered least relevant since it did not provide meaningful questions that probe thinking. It was expectable for the research team since the socio-demographic data was most meaningful for the research purposes. The result is presented in Table 4.5.

In theory, all of the perspectives measured by the six validated questionnaires in Monitor My Grief were related to bereavement outcomes or psychological states that could assist to map the bereavement experiences. We also wished to evaluate the participants’ comments on the relevancy of the 6 questionnaires and of receiving the feedback after completing the questionnaires. Assessing the relevancy and suitability of the questionnaires and feedback based on empirical data could provide more insights on the potential benefit or risk of including a certain questionnaire. In the assessment, we tried to understand participants’ experiences by observing participants reactions before entering the questionnaire (e.g., participant felt curious or excited by reading the description of the questionnaire), when answering the questions (e.g., participants felt confused by the questions) and when receiving the feedback (e.g., participants laughed when reading the feedback, or participants commented that the feedback was “lovely”). The assessment of each questionnaire is presented below.

### 4.6 Discussion

The preliminary test of GIFT yielded fruitful user experiences insights for a better UX design in the final deliverable and assisted the researcher to optimize the data gathering mechanisms for the next study. In this section, we look into the following five aspects to extract design implications for further improvement in data gathering mechanisms and user experiences of GIFT: participants’ experiences of support seeking on the Internet, the potential benefits/challenges of a grief self-monitoring app, language use in the bereavement context, navigation of the app and the functionality of the app.



Table 4.4 The socio-demographic data of the protocol analysis participants

Participant	PA1	PA2	PA3	PA4	PA5
Device	iPad Air	iPhone 6	iPad	MacBook Air	iPhone 5S
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	Grand-daughter
Marital status	Widowed	Married or living together in a committed relationship	Single	Married or living together in a committed relationship	Single
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

Participant	PA1	PA2	PA3	PA4	PA5
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 4.5 Participants' assessment of the experiences of answering the questions and the relevancy of the questionnaire for the Basic Information section

Questionnaire	Participants' comments
Personal Information	<p>Spiritual activity was confusing (PA1).</p> <p>Love the fact that the deceased name was embedded in the questions (PA2).</p> <p>Question #20 that asked about the frequency of contact with the deceased was triggering (PA2).</p> <p>Some questions need to clarify if it was about the griever or about the deceased (PA5).</p> <p>Mind the cultural perspectives when providing options for answering the question. For instance, the date format could differ in different country, the definition of a full-time job was 40 hours rather than 30 hours stated in the question, and the definition of formal education should be clarified.</p> <p>PA5 believed this questionnaire was least relevant for her.</p>
BRISQ (How do I experience my loss?)	<p>The most relevant questionnaire for the participants and the other grievers (almost all participants).</p> <p>The questionnaire took too long to complete (PA2).</p> <p>It felt connected to answer questions that were related to the deceased (PA2).</p> <p>Reminded the participant about how much support she had received (PA3).</p> <p>Could influence other grievers negatively because of triggering questions (PA3).</p> <p>Questions #14 to #18 were especially triggering for PA5 and she felt these questions brought her back to the time.</p>

Questionnaire	Participants' comments
CGRF (Are there specific things that affect my grief?)	Binominal answers were difficult and awkward (agree/disagree). Need spectrum answers for some questions (PA1 & PA2). Double negative phrasing should be avoided for grieving users (PA1 & PA2). Highly relevant for the griever (PA1). Felt guilty to say "disagree" when asked about whether the griever relied on the deceased before he/she died (PA2).

#### 4.6.1 Participants' experiences of support seeking on the Internet

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.

*"I found one article [online] that it wasn't even like a research. It's just this woman lost her brother, and I was like thank you. She described the first couple weeks, and that's the kind of thing I am connected with."* – PA2

Another participant indicated that grief is too personal and she would not look for support on the Internet.

*"I think when you are dealing with something as personal as grief. You'd better off looking for someone or finding someone who knows if someone who already has a personal relationship with the grief counsellors...I would think it would be the same thing looking into any yellow pages, which I wouldn't do either. I really think grief is just too personal and you need to have someone who's experienced to walk that walk."* – PA1

Keywords search was the most frequently adopted strategy reported in the sessions when the participants sought support on the internet. In general, Internet sites, blogs, 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 knew 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. However, blogs, articles, news, comments that did not necessarily offer authentic or systematic

Table 4.6 The assessment of each questionnaire

Questionnaire	Participants' reaction when answering the questionnaire	Participants' reaction when reading the feedback
PG-13	<ul style="list-style-type: none"> <li>#3 caused a lot of confusions because it combined many conditions together.</li> </ul>	<ul style="list-style-type: none"> <li>Participants experienced system problems so no feedback was provided.</li> </ul>
CESD-R	<ul style="list-style-type: none"> <li>Time was confusing for the participant. Was it taken based on the experiences in the past week or one week "after loss" (PA2).</li> <li>Questions were triggering due to loved one's death (PA3).</li> <li>Feel the need to know if he/she really has depression (PA4).</li> <li>Feel rewarding to have a track of the past week (PA4).</li> <li>PA3 believed it was least relevant and did not apply to her.</li> </ul>	<ul style="list-style-type: none"> <li>Sensitive feedback (PA2).</li> <li>Feedback should acknowledge the grief effort (PA4).</li> <li>Canned feedback, not adherent to the answer (PA5).</li> </ul>
PTSD	<ul style="list-style-type: none"> <li>Questions were easy to answer (PA2).</li> <li>Never thought about the connection between PTSD and grief (PA2).</li> <li>Stress was a broad term and could confuse the user if the user was stressful but not because of the loss (PA5).</li> <li>PA2 believed it was the most meaningful questionnaire for her.</li> </ul>	<ul style="list-style-type: none"> <li>Brought more awareness around grief (PA2).</li> <li>Get credits for coping with the trauma (PA4).</li> <li>In general, the most liked feedback among all of the feedback (PA2 &amp; PA3 &amp; PA4).</li> </ul>

Questionnaire	Participants' reaction when answering the questionnaire	Participants' reaction when reading the feedback
CD-RISC-10	<ul style="list-style-type: none"> <li>Enjoyable process to answer the question (PA2&amp;PA4).</li> <li>Fishing for adaptability (PA4).</li> <li>Lots of positively framed questions (PA4).</li> </ul>	<ul style="list-style-type: none"> <li>Feedback was encouraging (PA2).</li> <li>Good way to get a benchmark of positive mindset (PA4).</li> <li>Didn't provide any new information (PA5).</li> <li>PA2 believed the feedback of resilience was highly relevant for her.</li> </ul>
ISLES-SF	<ul style="list-style-type: none"> <li>Captured how the griever felt at the moment (PA4).</li> <li>The questions could be interpreted in a growth mindset (PA4).</li> </ul>	-
PTGI	<ul style="list-style-type: none"> <li>It felt like a little present from the deceased loved one (PA2).</li> <li>Surprised in a positive way to see benefits of losing a loved one (PA3).</li> <li>PA2 believed it was least relevant for her, while PA3, PA4 and PA5 indicated that it was a nice scale to end with.</li> </ul>	<ul style="list-style-type: none"> <li>Visual of chart is motivating (PA3).</li> <li>Pleasant visual conclusion (PA4).</li> <li>The feedback was very personalized and relevant (PA5).</li> </ul>

instruction of how to deal with grief might instead confuse the users. One participant thought that it was completely different from her experience and turned to a therapist because she could not believe what she found on the internet.

*"I remembered after [my loved one] died, I was like ... isn't there seven stages of grief? What exactly is that. And I looked it up and I was like what the hell is it. This is a bunch of Boloney. And then I was talking to the therapist about it, and she was like, that's not even what that was made. And like...this is a bunch of crap. Because this isn't nothing like what we are going through."* –PA2

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.

*"I actually got into grief therapy because my previous therapist said grief is probably playing on a large part. I might have googled it a little bit, like how you could affect you."* –PA5

Internet has become an inextricable part of our everyday life experiences; however, it has not been considered a completely trustworthy resource for support seeking. In the pilot sessions, it was at best considered a good source of self-referring of grief therapy and reading materials. One participant (PA4) specifically stated that he did not think of looking for an app on the Internet but simply looked for reading materials such as blogs or articles. Our finding revealed that gaining trust from the bereaved users, despite the easy accessibility of an internet site, can be potentially challenging.

#### 4.6.2 The benefits and challenges of a grief self-monitoring app

GIFT was targeting on the bereaved who were in the early phase (from zero to six months) of their bereavement. It was hypothesized that the bereaved could experience a significant life disruption and emotional impact during the early phase of the bereavement and needed an instrument to help the decision makings. The participants were asked to reflect on the general experiences of using GIFT and the potential benefits/challenges of using the app in the early phase of bereavement. Most of the participants were satisfied with GIFT and found the feedback relevant, authentic, reflective to their real situation and trustworthy. Some potential benefits were discussed as follows..

*Facilitate decision making.* GIFT was meant to enhance self-understanding and helped the users to make a decision in a traumatic situation.

*"I wouldn't rely on [the feedback] as being gasped but I would use the tool to make decision."* –PA1

*A tool for thinking and widens awareness of the bereavement-related aspects.*

*"it's a good conversation piece for family members that had experienced a loved one together. I mean it's hard to bring up grief to each other, because you don't wanna traumatise each other. But you also wanna talk about it. And this is something that's gauged in scientific and ... it is about our own selves, and that we have a common conversation."* –PA2

GIFT was a tool that enhance self-referring from griever who obviously need grief counseling.

*"I think you pretty much have an idea about how it's affecting you, but you may or may not know that you need to go seek outside guidance, that you may need to do something proactive rather than reactive."* –PA1

*“if they are getting help, just to make sure that it is specified grief therapy, not just happy counsel therapy, which is great, but people need grief therapy.” –PA2*

*“I guess [grievors] are curious as in how impacted they are. (interviewer: so it could help them realize how their grief is affecting them?) Yes.” –PA5*

*The process of using GIFT was therapeutic.* One of the participants (PA4) thought that using GIFT was “surprisingly therapeutic” and the feedback itself was a therapeutic lever that helped users to acknowledge the various aspects related to bereavement.

*“The way you give someone a profile themselves after they answered this, it also presumes like a therapeutic lever that’s get pushed. So I am kind of imposing my notion of a therapeutic lever, it’s not only affirmative, but more empathizing acknowledge and then acknowledging a mix of messy and pretty.” –PA4*

*The feedback was trustworthy and reassuring.*

*“I thought maybe I am ok, but I still need the reassurance that I am not going over the edge of times. Like I am already thinking about my parents or my brothers. Like I am already thinking about the people that I would hand this off to. Like “just go do this,” “it’s just an indicator.”” –PA2*

*“I think if you use the app, and people who go through it could say that maybe this is bothering me more than I thought it was. with the feedback I was right about where I thought I was.” –PA1*

Participants also indicated some potential challenges for using a grief self-monitoring app like GIFT.

*It was hard to focus if the process took too long to complete. In the case of GIFT, the session took in general 45 minutes to 60 minutes. However, the overall estimation of completing all of the questionnaires was expected to be less than half an hour.*

*“If I was suffering from depression, I would need to know that if I need to do this with no interruptions, or can I come back and do it. Is it, am I able to do it for 20 minutes and put it down, is there a time out session? And come back to it in an hour or two? So that might be helpful.” –PA2*

*“Too long to do in on sitting. Need to be able to save it and return to it. Overwhelming. Difficult to focus for long.” –PA3 (derived from the note of interviewer)*

*Providing feedback based on the score could result in users think it was a “Canned,” or untailored feedback.* Only one participant mentioned that the feedback seemed untailored because it directly contradicted to the answer she provided in the questionnaire.

*“I don’t know if it’s just like a canned response or something, but I know in my question*

*answer that I specifically said “not at all” on a question that asked me if I was unable to eat or not. But in the response it says if you’ve lost your interest in eating, that’s part of the feedback. (interviewer: so you’re saying that the feedback wasn’t really tailored to your answer because it directly contradicted the information that you already gave ). Yes.” –PA5*

*Technical challenges in different/older version of devices.* A severe technical problem was encountered by one of the participants (PA5) because she was using the older version of the mobile phone and the browser could not successfully support javascript or jQuery. It was particularly hard for the participant to go through the app on the mobile device since all of the questions and scales were completely collided together and overlapped with each other.

*The slider scale required some time to get used to, but participants grew accustomed to it after several questions. –PA4*

*Participants sudden emotional response in the middle of the session.* Two participants (PA2 and PA5) experienced sudden emotional moments or became tearful when encountering triggering questions such as the questions asked about how frequent the user was in contact with the deceased loved one.

*interviewer: and when you said that this is where the triggers kicked in.*

*PA2: yeah, I was thinking like how often did you have contact with him...that’s hard... (tearful) because I clicked 2-7 times a week. That’s hard.*

On the other case, the participant did not know if she should take a break when she felt difficulty to continue with the questions, she decided to continue because she did not want to lose her place in the questionnaire. The future app should take into consideration to save the users’ progress and be sensitive to the necessity to take a break and come back to the session with where they left off.

*“now I am on #18 (start crying). (interviewer: do you need to take a break?) I don’t know. #14 to #18...it’s just a little difficult because it takes you back to the time. (interviewer: so those questions were rather triggering for you.) yes. Just don’t wanna stop cuz I am gonna lose my place.” –PA5*

*The instructions of the questionnaires needed to be highlighted and emphasized so participants would not oversee them.* From the sessions, it was clear that sometimes participant failed to notice the important instruction of the questionnaire and got confused in the middle of completing the questionnaire and then was reminded by the interviewer to review the instruction.

One participant got confused by the 13<sup>th</sup> question in the CESD-R questionnaire and went back to the instruction to realize that it was asking about the past week. If a therapist was next

to a user, it was easy to emphasize essential instructions before a user rushed into the main content of the questionnaire. However, in the context of using a self-monitoring app, it is hard to imagine that users would be accompanied by a professional who knows what to notice in a questionnaire. Sometimes even the participant read the instruction, he or she could oversee the critical conditions of doing the questionnaire. Consider the following issue happened in our session.

*interviewer: did you read the instructions?*

*PA2: Yes, (read the instruction again)...*

*interviewer: in the past week.*

*PA2: Oh, sorry! (laughing) sorry, I did not read that. Because I'm like...I don't know.*

*interviewer: but it was good to know that you didn't see that part of instruction.*

*PA2: so I guess I am confused because I feel like, I read do I have depression? So I am on board.*

Participant (PA2) believed that she had read the instruction but ignored the most important condition that should precede to doing the questionnaire. It was still not clear until she was reminded by the interviewer. It was particularly interesting and challenging. This kind of issue should be avoided by a better interface design or a more condensed, shorter instruction that quickly informed users what they should bear in mind before starting the study.

*Not very applicable for users who have experienced multiple losses of loved ones at the same time.* One of our participants (PA5) has experienced multiple losses in the same time and needed to choose one to proceed in the app since the app intended to personalize the questions with the name of the deceased. It was hypothesized that multiple losses could cause bereavement overload for an individual and was a risk factor. However, the applicability of GIFT to the bereaved who have experienced multiple losses should be further studied and validated. In current version of GIFT, we should indicate that it mostly applies to the grievors who are bereaving the loss of one person.

Participants believed that GIFT felt incomplete at times but possessed the potential provide trustworthy and accurate feedback. They also encountered difficulties not knowing which questionnaire to start with and struggled with missing important instructions in the questionnaire and long session. Some of the challenges could be divided into navigation, language used and functionality of the app, which would be discussed in the following sections. It could be suggested from the participants' experiences that authentic information and accurate personalized feedback which could contribute to empowering the bereaved in the decision-making process (ex. To seek for grief support rather than happy counseling). However,

the instruction of using the app needed to be delineated clearly to the users. Two participants became especially emotional in the process of using the app and were guided to complete the study by the interviewer. At the end of the study, they had very positive gauge of GIFT, which implied that using such a monitoring app under the support of a therapist could also be a potential approach.

### 4.6.3 Language use in the bereavement context

The language used in the monitoring app and questionnaires should be easy to comprehend and appealing to the end users, which means that jargons or clinical terms should be very carefully considered. Even though these terms must be included to precisely describe the users' situation, the designers should make sure that they were thoroughly explained in an understandable language. In our sessions, we concentrated on three different aspects that require different considerations of sentence phrasing or keywords using, language use in the questionnaire, in the app interface and the feedback.

#### 1. Language use in the questionnaire.

*Engage the users with the first name of the deceased loved ones.* At the beginning of the study, participants were invited to enter the name of the deceased loved one that they were grieving for, and most of them entered the full name of the loved one. The name was then embedded in the questions to engage participants more. In general, participants liked it a lot but started feeling impersonal after the full name was repeated too many times. It was overall a great initiative since participants felt more personal and comfortable while completing the questionnaire.

*"Even I like how it says his name each time, maybe as we are going through, you can take his last name off. Cuz it feels a little impersonal. Now it feels formal. If it just said [the deceased's first name], then it feels more comfortable, personal." –PA2*

To avoid this kind of inconvenience, it was important in the future for the designers to consider using only first name of the deceased. However, it did not mean the participant (PA2) disliked this initiative.

*"reading about him. Just answering any questions about him. That feels connected." –PA2*

*Feels bad to disagree.* The phrasing of the question could also cause difficulty to give a negative answer if the statement seemed to suggest a certain normative perspective.

*"I didn't rely on him. But I felt bad saying "disagree." Cuz I didn't rely on him, cuz he wasn't like a partner. But I relied on him as a relationship. I am gonna put disagree, cuz I did not." –PA2*



*Negative/clinical words.* Negative words such as “bad” should be used with caution because it felt too morally judgemental.

*“on #9 [of the CESD-R], I feel like I am a bad person. Bad towards moral. But I think the other thing that people can feel, it’s more like ineffective, or letting people down. So “bad” has an after taste of moral. I felt like I’ve been letting people down around me because I’ve been depressed or down. I think someone should debate to use the word “bad.” –PA4*

In the interviewer’s notes, she also mentioned that “*complicated*” could be alarming to the users since it sounds too clinical. We did not find a specific quote in the recording, but it was worth noting. Sometimes negative or clinical words were necessary for the question, so it depends on the researchers’ intentions in designing the questions.

*Avoid double negative phrasing.* Some of the questions in CGRF were explicitly designed to capture “*risky*” thinking style, and we believed it was only meaningful when the users agree with the statement. For instance, “I have no one I can talk to openly and honestly about my grief” addressed the risk factor of lacking social support. It would only be more meaningful if participants agree with the statement. In this regard, the strategy of phrasing the question should be adjusted based on the evaluation of importance between capturing the risky circumstances or making the sentence straightforward and precise.

*Scaled answers for questions that asked to gauge the degree of feeling.* Providing a spectrum for certain items that assess importance or degrees of feelings: in CGRF, some of the questions should come with a scaled answer rather than a binomial answer such as “agree” and “disagree.” For instance, a question asked about the importance of religion was phrased like “religion/faith/spirituality plays a major role in my life.” Users should be provided scaled answer to indicate the importance of religion in their lives. Almost all of the questions were provided a 5-point Likert scale in BRISQ, so BRISQ has not received such a comment. According to PA3, in the context of dealing with grief, individuals might feel frustrated if they were to be asked to answer a yes/no question. It is suggestive to avoid the binominal questions in the particular context.

*“I think I almost feel like the “agree” “disagree” as a little difficult... [when bereaving for the death of a loved one] I am so much more scattered than I used to be. So it’s hard to focus. You know. As simple as wording can be, or I think it’s helpful especially for somebody dealing with grief. Cuz I know I had a hard time remembering things, or focusing. So maybe “agree” and “disagree” is a little awkward...and having to re-read something, it’s easy to get frustrated or discouraged. and if you feel that you have to keep re-reading things. It can feel very...defeating. This is something that I should be able to do.” –PA3*

*Avoid vague or intrusive wordings.* Participants were confused by the wording such as “traumatic” experience, “romantic” relationship, or “recent” loss. Any words that required a gauge of degree could confuse the users and should be used with caution or with clear definitions. For instance, adding “by recent, we mean in the past three years.” Asking a circumstance with a predefined condition could cause a participant to doubt the applicability of the question. For example, lingering “illness” would not apply to every kind of death. The deceased might not die because of an illness but lingering/suffering did apply to the situation. Researchers should consider the type of loss in the future and customize the wording based on the circumstances. In this case, BRISQ was a questionnaire used in identifying individuals who have encountered a death of a loved one due to cancer. The content might need to be adapted to fit in the app in the future.

*Differentiate “loss” and “death.”* In the bereavement context, a death meant the event itself, the event that a loved one passed away. Loss was sometimes used to address death of a loved one in a more convenient and less-intrusive manner. Describing death of a loved one as a “loss” could be less emotionally disturbing. However, replacing death with loss in a question could imply many more perspectives. It could be interpreted as the loss of a person, a feeling of loss or several aspects of losses following the death of a loved one. Consider the following misunderstanding in the session, although, in this example, the interviewer misinterpreted the question.

*PA2: #20 so I feel overwhelmed by the number of recent losses I have experienced, but not multiple.*

*interviewer: By that you mean that there aren’t multiple death, but there are multiple losses inherent in [your loved one]’s death. (PA2: got it.)*

*PA2: that makes sense. Yes, if you listed out all of the losses that came with his death, then yes. I read as recent losses meaning multiple people have passed. (interviewer: ok, not necessarily.)*

*PA2: so that would be more clear if it’s phrased as “recent losses in relation to [my loved one]’s death.”*

If a loss must be used to replace death in the question, then researcher should clarify that the question was asking about how many losses “of” family members or friends. If the researcher intended to inquire the types of loss the users have experienced following the death of a loved one, then the participant has provided a nice suggestion, adding “in relation to the death of my loved one” in the end would clarify what the question was inquiring.

## 2. Language use in the app interface

*Warning/instruction about time and potential emotional triggering in the process in the beginning.* Participants indicated that the session took longer than they have expected and they were more

triggered by the question than they expected. There were in general nine questionnaires in GIFT, with the first three questionnaires being highly connected to the loss experiences and bereavement process. For the designer and researchers, it was more than expectable that the questionnaires could trigger emotional responses, and we tried to provide emotional lever by offering feedback at the end of some questionnaires. However, if users entered the app thinking that it was a monitoring tool rather than being “scouted” about the overall bereavement circumstances to receive thorough feedback, they could encounter frustration, tearful moments, and anger in the process of using. Researchers are suggested to be more aware when including emotionally triggering questions in the app and provide relevant warnings to the users in advance. In the case of GIFT, the warning was placed in the informed consent form, but few users would pay attention to the legislative document. To provide the warning and prioritize it when the users enter the app would be the task for improvement in the future.

*Emphasize the duration to complete a questionnaire.* How long it takes to complete the questionnaire should be emphasized, so the users know what to expect. In the GIFT, the expected completion time of each questionnaire was mentioned but was easy to be ignored. One of the participants mentioned that users should be prepared for a long session.

*interviewer: so even if the app does say how long the session is gonna take, it wasn't obvious to you how long it took. (respondent: right)*

*PA2: the chunks [of instruction] are helpful. But if you are gonna sit down and be alright, you've got 4 glasses of wine and you'll get 60 minutes into this. OK. Get some chocolate cuz you're diving in.*

*Simplify the redundant parts.* In PTGI, each answer was followed by “as the result of my crisis.” It sometimes could irritate the users by including the complete sentence. The better adaptation would be to remove the repetitive clause in the slider and only prioritize the critical content.

*“I would not repeat “as the result of my crisis“ all the time, I'd like the sentence to be simpler and tier up the scaling as the result of my crisis. Cuz I felt like my mind was getting jumbled. It irritates me, honestly.” –PA4*

### 3. Language use in the feedback

Four out of five participants appreciated the feedback and thought that it was informative and reassuring to their current situations. PA5 thought that the feedback still stayed in a superficial level rather than providing substantial information. It could be because the feedback was drafted based on the overall score of the questionnaire and one of the statements directly contradicted to a specific answer she provided in a question. In the app, all of the questionnaire titles were replaced with question sentences instead of the name of the disorder or psychological states that

they measured. For instance, “*how complicated is my grief?*” for PG-13, “*do I have depression?*” for CESD-R or “*how much meanings have I found in my loss?*” for ISLES-SF. Participants appreciated it and reacted such as “*this is interesting! I've been wondering if I have depression.*” (PA4). Below we listed three potentially noteworthy suggestions that should be considered in the future drafting of the feedback manuscript.

*Make the feedback meaningful even when the result is negative.* In the session, when participants read the feedback and got a positive result (e.g., higher resilience, or no depressive disorder), they often felt encouraged. Consider how PA2 responded when receiving the feedback in the CD-RISC-10 questionnaire..

*“This is great little snippets. Your personal optimism ... well written. Did you write that? That was very lovely. I love the way that all of these have been written so far. Very encouraging.” –PA2*

However, in the case of PA5, she expected negative feedback and knew that she was not performing well when going through the questions in the questionnaire, and when the result confirmed her hypothesis, she felt that the app did not provide any new insights for her.

*PA5: If you are answering the questions they are asking, you already kind of know. Like...no, I don't do this well, or else I wouldn't be here.*

*Interviewer: so you don't feel like it provided you with new insights.*

*PA5: no.*

It was understandable that the bereaved individuals cheered for positive results and felt rewarded after receiving positive feedback in the questionnaires. However, in this particular context, it was of crucial importance how to deliver the “bad news.”

Besides reinforcing the users' hypothesis that they did not seem to perform well in the measurement, which might be more than evident to the users, writing the feedback in a more hopeful, encouraging, or empathic tone could be a significant challenge for researchers and developers.

A potential way to make the result more meaningful without diagnosing the users could be acknowledging their negative feelings and effort to cope with grief even though they knew they were not doing well (derived from the experiences of PA4). Consider the following quote from PA4.

*“You expose yourself to have an open wound, and through that you're still basically a healthy person...[acknowledging] it would also give more credits that you can be a whole and complete person while feeling incomplete and broken.” –PA4*

Another potential strategy was to include the hopeful side of the bereavement and

reinforce the possibility that users can go through it with concrete evidence and suggestions (derived from the experiences of PA2). More examinations and users' experiences sharing on the feedback would benefit the development of it.

In the GIFT study, we were under the regulation of IRB and could not provide any diagnosis or suggestions which required intense clinical investigation. Motivating users to refer to a psychotherapist if their answers implied problematic coping outcomes was the best outcome GIFT aimed to achieve at the current stage. However, how to successfully connect to the supportive resources or crews and to support the normal griever in the coping process should be taken into consideration in the future development.

*Acknowledge the effort of grieving.* Participants pointed out that their effort (or even negative feelings) during the process of coping with bereavement should be recognized. It would be less meaningful if the feedback simply stated that they performed well, it would be much more reflective to disclose their problematic feelings and situations. However, the feedback should be worded in a manner that could acknowledge the effort rather than simply reinforce the negative truth.

*"[The feedback from PTSD questionnaire] recognizes that your stress is complicated, the fact that you have feelings that occur that are problematic that you overcome and you get through, but you're also coping and you're moving ahead. The [feedback from Depression] was more candy land a little bit." –PA4*

One aspect that worth noting was how to be sensitive about the "grieving" work in the bereavement period. PA2 mentioned that others did not ask about how the participant was grieving, they asked about how she was doing. However, it would have been great if individuals were sensitive to concern about her grieving situation or about what she has done to deal with the loss.

*"not very many people asked how I am grieving. They asked like "how I am doing," but nobody asked how I am grieving. Oh my gosh, wouldn't that be nice? (laughing) That'll be nice if people said what are you doing to help yourself or to honoring [the deceased] and then...no, nobody does that." –PA2*

The result suggested that the bereaved wished to be concerned not about how they performed at the moment, but about how much effort they have spent in coping with the grief and honoring the loved one. This was an interesting insight since according to the participants, griever knew that they were in a sad moment, and did not necessarily appreciate other people's kind concerns about how they are doing, but might appreciate questions that tried to understand what coping strategies they have adopted to pull through.

*Avoid contradicting to the answer to a question.* The feedback in the app was drafted based on the overall score the users receive at the end of the questionnaire. However, in the case of PA5, the statement of the feedback directly contradicted to one of her answers to the previous question. Then PA5 thought that the feedback was "canned" feedback and was only addressing a superficial level of her experiences. It did not suggest that the result of the questionnaire was less accurate since CESD-R was a validated diagnostic tool, but the feedback drafting should also be sensitive to the answers to the relevant questions and avoid contradicting to the answer directly.

#### 4.6.4 Navigation design of the app

*Red text or red button should be used with caution.* The bereaved could be highly sensitive to any warning signs or warning messages. In the process of completing the questionnaire, PA3 became highly alarmed and started doubting if she had done something wrong or if something wrong happened by giving a certain answer to a question. For the bereaved who were at the early phase of their grief, any type of design that could trigger the feeling of alarm or warning could be dangerous and should be absolutely avoided or used in caution. Compare the following two situations happened in the PA3 session. The designer has selected a dark red to display the answer in order to differentiate from the dark blue title.

When PA3 answered a question in the questionnaire, the answer was displayed in dark red.

*"when you answer the question, and then it says that your answer is... I think that's great, but having that be red, that very first time happened I was like, oh, what did I do wrong? I felt, especially in the beginning [of the bereavement], it was like I didn't feel that I could do anything right. Like everything is going wrong. It's so small, but to have something like that kind of jar you. If you're gonna avoid it, it would be nice." –PA3*

When the system reminded PA3 that there were several questions left to finish in the questionnaire, she ignored it the first time but noticed at the second attempt to submit the entry. .

*PA3: it did say something [when I tried to submit the answer] but I just didn't read it. I think that popped up that you still have 3 questions.*

*interviewer: it goes with a delayed response?*

*PA3: a little bit, but maybe it was a little more. Maybe THAT wasn't red. Like, hey you still have some questions to answer, and I would realize that I did something wrong.*

Red or any types of color that are close to red could easily trigger alarm feeling to the users, which was not limited to the bereaved users, should be treated carefully and used only when necessary. Selecting a red color with less saturation or brightness could be helpful to ease the warning feeling.

*Indicate the next questionnaire to visit.* The researcher should pay attention to the difference between mobile navigation and large screen navigation: on the larger screen, the questionnaires were separated into two groups and placed horizontally within each group. This design provided a weak indication to the participants who used tablet or laptop. Two out of five participants asked about which link to visit next but also appreciated that the block of the questionnaire turned transparent after the questionnaire has been completed. Participants naturally went from top to down, left to right in completing the questionnaires. So most of them completed the questionnaires in the same order as the researchers expected. On 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. Since, for GIFT, all of the questionnaires should be completed to complete the session, it would need a very indicative / perhaps vertical layout to enhance the navigation.

*Deal with questions that were skipped.* The six questionnaires in the Monitor My Grief section were validated questionnaires, and hence if even one question were skipped, the app would not be able to offer precise feedback. The system was programmed to prevent submission if the users did not complete the questionnaire and there would be a pop-up window notifying the user that how many questions they have not completed. In the pilot test, it was hard for users to notice the pop-up window and the external experts provided a suggestion to either list the number of the uncompleted questions or scroll back to the spot where the question was. Designers should also provide clear visual indication, such as changing the background color or bolding the font or adding warning messages to hint that the questions have not been filled.

*Deal with questions that had a long list of answers.* In the background questionnaire, the questions asked about nationality was provided with a long list of country names. Participants thought it would be better to be able to type and search for the country name instead of fumbling in the list for their countries. It would also be better that the participants could type and search for relevant answers to the question that asked about religion.

*Various types of answers in the questionnaire.* The personal information inquired the socio-demographic data related to the participants and the deceased loved ones. Some of the open questions could cause difficulty both in answering and in analyzing. For instance, the format of date appeared confusing. 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. For the questions that allowed open answers, such as “how many” deceased loved ones the participants had also experienced in the past three years, participants appreciated the keywords placeholder in the input column.

*The context 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, implying that participant would appreciate a certain period of engagement in the app.

*The app should 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 in a clear and explicit manner.

*PA2: does it say at the beginning of the app how long this could potentially take? For the questionnaire?*

*interviewer: I recall it says 60 minutes. Did you notice that it does say that under each one questionnaire.*

*PA2: Oh, yeah, I didn't notice it. Cuz I could see someone opening this app and being like...God hold on, how long do I have to do this...and go to a quiet place cuz my kids are home there can be some triggers that might upset you.*

*Emphasize important information by bolding and changing the color of the text.* 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. In the session, participants also encountered difficulty in reading the question and went back to the instruction and realized that it was asking for a certain period.

*Provide instruction for the slider design.* The sliders in the questionnaires were nice, but there should be instructions on 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. Participants did not have problems getting accustomed to the usage of the slider. 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 third Likert Scale item. For instance, from “Strongly disagree” to “Strongly agree,” the default option was placed in the middle “Neither agree nor disagree.”

Researchers could choose to place the default option in the beginning or at the end of the bar, or completely remove the default option. Placing the default option and placing it in the middle was a better choice in the study since the bar itself did not indicate any means of



“sliding” left or right, so it needed a handle to hint the users; and we did not wish to prioritize the positive or negative responses in any of the questionnaires. 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.

#### 4.6.5 Functionality of the app

*Share the report with others.* Participants would appreciate if they could send the report to family members or close friends through email and share with them how they were grieving. It could also become a “conversation piece” with family members (PA2). For the future development of GIFT, it would be a beneficial function to allow users to share the report through email or on the social media.

*Save the in-progress data.* Although the questionnaire entry was automatically saved after the participants submitted the questionnaire, it was not explicit to the participants. Some participants went back to the questionnaire and saw a completely blank questionnaire thinking that their answers were not saved. It should be avoided. Whenever the app saved the data, it should provide notification that the data was saved in progress, and the users should have a mean to review their data entry.

Two participants (PA2 and PA3) specifically mentioned that the bereaved felt hard to focus and tend to want to drop out in the middle of the session. PA4 also revisited the questionnaire in the middle of a session and realized that the questionnaire was blank, which confused and frustrated him. The app needed to provide a “time-out” option or allow users to save their progress and revisit the questionnaire with where they left.

When PA5 was asked about her feelings about the relevancy of the questionnaires, she answered “*like right now, I couldn’t even remember what they were.*” Bereavement could occupy a majority of an individual’s attention and they needed to take a break from the session. Adding a save button, or making it explicit that the progress was save is imperative in lessening their stress in the process. It also could prevent users from accidentally exiting the page and losing the progress data.

*Link to other bereavement-related resources or refer to the therapist.* One of the essential features of a self-monitoring app is to link to useful resources when the users needed. The helpful resources mentioned by the participants included blog articles, books, counseling websites, contact ways of a grief counselor. It was also suggestive that the resources were feed according to the users’ result. If the users were at higher risk of developing PGD, they should be referred to a grief counselor

instead of reading materials such as books. However, for a normal grieving user, it would be less meaningful to refer him/her to a grief counselor.

## 4.7 Limitations

Bereavement is an emotional journey that could be significantly influenced by an individual’s cultural background and/or religious affiliation. The wide accessibility of an internet-based self-monitoring app does not necessarily guarantee that it would appeal or adhere to the needs of users from various cultural backgrounds. In this study, we mainly concentrated on the bereaved population in the USA because of two reasons, the available literature and the composition of the research team. A great number of available studies and measurement tools were targeting on western populations and would be applicable mostly to the sample that from similar cultural and religious background. All of the questionnaires and feedback were written primarily in English and were meant to be administered to English native speakers to reach the best sensitivity and complete experience of using GIFT. The composition of the research team also enabled researchers to have best network and resources in recruiting participants and acquiring development support within USA and the Netherlands. However, to administer the app in the Netherlands would require us to translate all of the materials into Dutch and could generate difficulty in combining the results. Furthermore, the content of the three in-progress questionnaires in Basic Information might be altered after the pilot study. Therefore, we decided to focus first on the USA population for validating the predictive model and plan to conduct the multi-cultural study in the future.

## 4.8 Conclusion

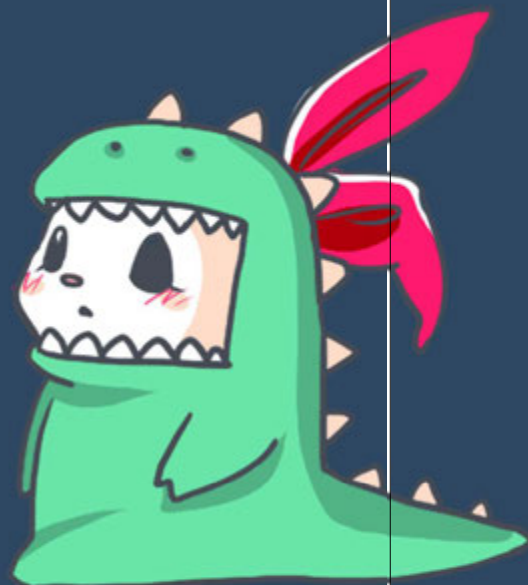
Disregard the strong necessity to enhance the navigation and user experiences of GIFT, from the preliminary test, we could conclude that the insights gathered could enhance our knowledge on what data should be gathered to build a robust predictive algorithm of PGD and what UX factors should be considered for a better users experiences in interacting with the internet-based self-monitoring system. Alone with the design of the data gathering prototypes, 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 [1, 55]. Furthermore, the Internet likely also serves as a medium of communicating



and connecting with the deceased [19, 20, 61]. The effect of these phenomena remains unknown both in an intra and interpersonal level but is by far worth heeding. More results from the future studies will contribute to informing the field and professional practitioners how to better support the bereaved in the early phase and facilitate positive health outcomes by not only offering psychotherapeutic interventions but also preventive ones.

# COST OF LIVING IN NETHERLANDS

Sometimes international students got freaked by falsely assuming that living in NL can cost you a fortune.



Originally published in  
Oranje Express  
Jun 11, 2016



## Chapter 5 Fitting and Evaluating Three Regression Models to Screen PGD with GIFT

GIFT is motivated by the literature reviews on risk factors. Although focusing on the risk factors seem to be a promising approach, the contribution of each hypothesized risk factor on the dependent variable (PGD) is unknown. An empirical study is necessary to build the screening model that validates the contribution of each proposed risk factor and explain the variation of the dependent variable. There are two different apps developed and deployed for fulfilling the research objectives at different phases of the research. GIFT is developed to gather data regarding predictive factors (quantitative) and design insights (qualitative). The final deliverable of this thesis is a screening PSS developed based on the structure of GIFT and the regression model fitted with the gathered data. For a better differentiation, the final internet-based screening method is titled Empowered to Grieve (abbreviated as EtG in the following paragraphs), which targets on only screening PGD rather than providing various types of feedback to grievers like GIFT.

The first section reports the change in functionality, language use and interface of GIFT based on the findings in Chapter 4. The lesson learned from observing our participants through the protocol analysis is that bereaved users are more prone to want to drop out in the middle of the session and they had a lower tolerance to the poor user experiences. Users also could ignore essential instructions in the questionnaire and then provide answers that were not representative of their situation. Section 5.1 describes the strategies to deal with the observed issues to avoid interfering the data collection.

Section 5.2 describes the study setting to deploy GIFT through the internet, including the ethical consideration and concerns of data security. In general, conducting studies that involve collecting potentially identifiable data from participants might require extra review procedure depending on the regulation in the study country. Caution is advised toward collecting private information through participants on the internet, and normally an HTTPS protocol should be

implemented to secure the data transmission process. These concerns are presented along with the study design, the procedure of extracting the data, removing incomplete data from MySQL database and code the data in SPSS. The statistic method implemented to analyze the data will be introduced and explained in the section as well.

The socio-demographic results of the participants are presented in section 5.3, followed by the three models fitted with the three groups of PGD predictive factors, background factors, bereavement risk factors and bereavement outcome factors. One model is selected from the three models for further implementation in EtG. We then compare the three models and discuss the contribution of various predictive factors to PGD in section 5.4. The qualitative results including participants' story sharing and comments about their experiences are reported in section 5.5, followed by section 5.6 of general discussion.

Section 5.7 describes how the selected predictive model (formula) will be implemented in EtG. Section 5.8 concludes the study with potential limitations and future research opportunities.

### 5.1 Implementing GIFT as an Instrument for Study Data Collection

The user data and questionnaire results of GIFT are stored in the database powered by MySQL with multiple tables corresponding to answers of different questionnaires (a sample data structure diagram is displayed in Figure 5.1). Since SPSS is expected to be the software used for data analysis, each questionnaire data was stored in a single table with the number of rows corresponding the number of questions. This design allows researchers to interact with the data directly and quickly extract the results of the questionnaire for further analysis.

Before deploying GIFT to the end users, we made some modifications to the language, navigation features, and functionalities based on the insights gathered from the protocol analysis. In the current phase of app development, we prioritized the functions that were more related to data collection and data extraction. Hence some of the user insights reported in Chapter 4 were not entirely implemented in this phase because GIFT was not ready to be tested as a self-monitoring app. The changes and concerns of modifications of the app are presented below.

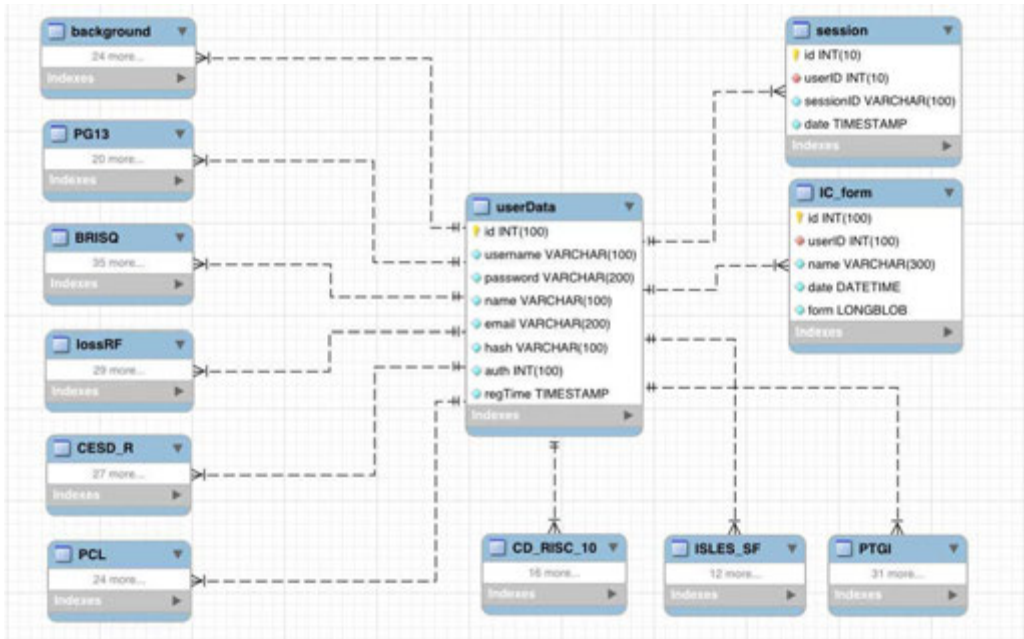


Figure 5.1 Diagram of the data structure

5.1.1 The language use of GIFT

GIFT will be deployed through the internet, and the users could access the app from a variety of channels. Therefore, in comparison to the protocol analysis, users are not expected to complete the study with a professional counsellor, which immediately raises concerns regarding the frequently observed frustrations caused by the wording in the questions or the questionnaires. For instance, users were triggered by the questions and became emotional, or users were confused by the double negative phrasing of the questions and had to reread it. These experiences could easily cause frustration and annoyance that lead users to drop the study in the middle. In the previous chapter, we have discussed the different concerns of language use in three different dimensions, all of which were critical to not only avoid misleading users and collect precise data but also attend to users’ potential severe emotional responses and annoyance in the study process. In this section, we present how GIFT is modified to eliminate the poor user experiences caused by the wording in the various aspects of the app.

1. Language use in the questionnaires

*Change in questions phrasings of CGRF and BRISQ and add scaled answers to CGRF.* Two major issues to solve were the double negative phrasing and binominal responses in the

CGRF. CGRF was designed to capture risk factors through four perspectives, personal factors (e.g., insecure attachment style), relationship with the deceased (e.g., pre-loss dependency), relationship with others (e.g., low social support) and the death-related factors (e.g., hard to make sense of the death). It is more important when the griever appraised the event negatively. For instance, changing the following sentence, “I feel uncomfortable letting people get close to me emotionally” into “I feel comfortable letting people get close to me emotionally” does not seem to capture the risk psychological state as precisely as the original one. If a user disagrees with feeling comfortable letting people get close to him/her emotionally, it does not immediately indicate that the user is uncomfortable letting people get close to him/her emotionally. In the end, we decided to rephrase most of the questions into positive phrasing and keep two questions that are especially meaningful when negatively phrased in the original phrasing. We then also changed the answer into 5 points Likert Scale answer ranging from strongly disagree to strongly agree. In this way, users could address their opinions in more depth. Three positively phrased questions were also reverse scored to capture the risk factors.

Since BRISQ was developed mainly for cancer-related bereavement users, it should be modified to be used on a more general population. The changes of BRISQ were primarily focused on the questions that asked two things together. We replaced “and” with “or,” suggesting that the users would be able to judge if the statement applies to their situations. The concept of CGRF and BRISQ is that if the score is higher (means that user experiences or agrees with the factors to a stronger degree), the users are exposed to risk factors to a higher degree.

Table 5.1 The title and introduction of the questionnaires in the app

Questionnaire	Title	Short introduction
Personal Information	Personal information about me and the person I lost	21 questions, 5-7 minutes
BRISQ	How do I experience my grief?	31 questions, 7-10 minutes
CGRF	Are there specific things that affect my grief?	25 questions, 5-7 minutes

Questionnaire	Title	Short introduction
PG-13	How complicated is my grief?	13 questions, 5-7 minutes Grief is a fundamental life experience and a natural reaction to the death of a loved one. However, sometimes the loss is just too intense, and we feel “stuck,” lost, or preoccupied for a very long time afterward. By completing this brief questionnaire, you can receive some brief feedback about your grief, and how it compares to that of other people.
CESD-R	Do I have depression?	20 questions, 5-10 minutes Grieving exhibits some responses that are similar to depression, but it usually does not interfere with your ability to continue living a meaningful life. This questionnaire helps you to monitor your depression level.
PCL-C	Do I suffer from Post-traumatic Stress Disorder?	17 questions, 5-10 minutes Post-traumatic Stress Disorder (PTSD) possesses several similar symptoms to grief but has its own characteristics, such as the tendency to avoid thoughts or reminders of the traumatic event and hyper-vigilance about perceived threats. This questionnaire helps you to clarify whether you are experiencing PTSD. If you are already diagnosed, it can help you to measure the improvement.
CD-RISC-10	How resilient am I?	10 questions, 3-5 minutes Resilience indicates a person's ability to “bounce back” in the face of trauma or stressful life situations. By completing this questionnaire, you will receive feedback on your resilience score and what it could mean for adapting to bereavement.
ISLES-SF	How much meaning have I found in my loss?	6 questions, 1-2 minutes Meaning making plays a pivotal role in coping with stressful life situations. This 6-item questionnaire offers a simple way to understand your ability to make sense out of your loss. By completing this questionnaire, you will be presented some feedback on your meaning making ability.
PTGI	What have I learned from loss?	21 questions, 5-10 minutes Although sadness is a normal response to loss, people sometimes experience positive gains from their attempt to cope with this reality. This questionnaire measures your posttraumatic-growth experiences in the following 5 areas: (I) relating to others, (II) new possibilities, (III) personal strength, (IV) spiritual change, and (V) appreciation of life.

*Clarify the vague wordings.* We either replaced some of the ambiguous words with more precise descriptions or added further definitions or gauge of the degree. For instance, romantic relationship was replaced with “committed” relationship and a definition of 3 months was added to explain the “recent” loss.

## 2. Language used in the app interface

Although most of the questionnaires names were self-explanatory, they might seem highly clinical and unappealing for the general users. The IRB reviewers also recommended that the researchers should avoid using jargons or clinical terms in the app, which might disengage the participants and trigger alarm feeling. In this regard, all of the questionnaire titles were replaced with questions. The titles should describe the symptoms or psychological traits measured by the questionnaire in a common language. The introduction should include the number of questions; the time takes to complete the questionnaire and the short description of the symptoms or the psychological traits (for the complete title and introduction of the questionnaires, see table 5.1).

## 3. Language used in the feedback

The feedback of each questionnaire should contain the following three elements, a visual gauge of the score, the implications or potential symptoms indicated by the score and a suggestion whether the user could benefit from visiting a clinician or a grief counsellor. A great amount of attention was placed on how to deliver the negative message and how to define the threshold of poor performance (for instance, in bereavement or meaning-making). The feedback of each questionnaire was written collaboratively by the researcher and one of the field experts. Below we list the feedback of each questionnaire result and describe the criteria for determining the outcome in GIFT.

*PG-13 for diagnosing Prolonged Grief Disorder.* As a diagnosing tool, PG-13 originally contains only two categories, normal grievers and chronic grievers [49]. However, it is very unlikely that a self-monitoring tool only gives a dichotomous diagnosis. To provide more insights based on the participants' score, the researcher of PG-13 was contacted to inquire about the precise grouping of grievers. The researcher of PG-13 proposed to use one standard deviation to distinguish the sub-syndromal grievers and separate the syndromal grievers with severe PGD grievers. It resulted in the following four groupings, PGD grievers, syndromal grievers, subsyndromal grievers and adaptive grievers. The criteria of determination and feedback of each group are described below.

Table 5.2 The grouping criteria and feedback of PG-13



Criteria	Feedback
PGD grievers  score higher than 43 and the loss is more than 6 months with significant social impairment	<p>Your grief score is X out of a possible 55. A score higher than 44 indicates that you could be experiencing a protracted and intense grief, which could be quite difficult for you to cope with on your own, despite your best efforts. You may find yourself preoccupied with the loss to such a degree that it is hard to function in other relationships, at work, or in daily life, with painful thoughts and memories of your loved one intruding even into those moments when you are trying to concentrate on something else.</p> <p>The score on this questionnaire does not intend to diagnose you; rather, it should be considered a chance to revisit your ways of coping with bereavement. Many people who report this degree of prolonged and intense reaction to a loss benefit from consulting with a therapist or a psychiatrist who specializes in bereavement care.</p>
Syndromal PGD  score between 37 and 43, the loss is more than 6 months with significant impairment	<p>Your grief score is X out of a possible 55. A score between 37 and 43 indicates that you exhibit a strong potential for developing prolonged or complicated grief symptoms. This means that your grief course is worth your attention since it could be very difficult to cope with your grief without any professional support. You may find yourself preoccupied with the loss to such a degree that it is hard to function in other relationships, at work, or in daily life, or could find that painful thoughts and memories of your loved one intrude even into those moments when you are trying to concentrate on something else.</p> <p>The score on this questionnaire does not intend to diagnose you; rather, it should be considered a chance to revisit your ways of coping with bereavement. Many people who report this degree of prolonged and intense reaction to a loss benefit from consulting with a therapist or a psychiatrist who specializes in bereavement care.</p>
Subsyndromal PGD score  27-36 & the loss is more than 6 months & significant impairment is confirmed	<p>Your grief level score is X out of a possible 55. Although your score on this measure of grief does not place you in the range of people who are likely to develop prolonged or complicated grief, your symptoms could be troubling enough to you that you would benefit from consulting a psychotherapist or physician who specializes in working with this condition, or from participating in a mutual support group online or in person for others who have had losses similar to your own.</p>
Adaptive bereavement  score under 26	<p>Your grief level score is X out of a possible 55. According to these results, you clearly do not exhibit a severe and prolonged grief response, and instead seem to be adapting well to the loss of your loved one, despite the sadness and longing that might be associated with it. Grieving stems from a heartfelt love for the deceased and is a natural reaction to a significant loss. It can be challenging but also adaptive.</p>

*CESD-R for diagnosing Major Depressive Disorder (MDD).* CESD-R is a robust and popular diagnostic tool for MDD and has a precise definition of each group [239]. Therefore, we implemented the grouping of the questionnaire directly and took a reference on the cesd-r.com website for the feedback script drafting. The difference between GIFT and the website was that the feedback was written from the bereavement-related perspective and mainly acknowledged the symptoms that are related to bereavement. Since the diagnose of MDD is not based on the score but based on meeting the criteria described in DSM-V, the overall score is not emphasised in the script [48]. The feedback would indicate that there are several forms of effective treatment for MDD and encourage users who exhibit certain potential of MDD to contact physicians as soon as possible.

Table 5.3 The grouping criteria and feedback of CESD-R

Criteria	Feedback
Major depressive episode  meet the criteria of Dysphoria and Anhedonia and exhibit serious symptoms of at least 4 other criteria	<p>Your answers suggest that you could be suffering from a major depression, with pervasive sadness, lack of energy and motivation, an inability to feel pleasure and a variety of possible disturbances in concentration, sleep, appetite, and other domains. At its worst, you may question your own worth, experience acute guilt and self-blame, or feel that life is not worth living. However, there are several effective forms of treatment for depression, and you are encouraged to contact your physician and a qualified therapist to assist you in overcoming this tragically common response to loss.</p>
Probable or possible major depressive episode  Meet the criteria of Dysphoria and Anhedonia and exhibit serious symptoms of at least 2 or 3 other criteria)	<p>Your answers suggest that you could be at risk for a significant mood disturbance, even if you do not meet full criteria for a major depressive disorder. You may be struggling with some combination symptoms such as pervasive sadness, lack of energy and motivation, an inability to feel pleasure and a variety of disturbances in concentration, sleep, appetite and other domains. At its worst, you may even question your own worth, experience acute guilt and self-blame, or feel that life is not worth living. However, there are several effective forms of treatment for depression, and you are encouraged to contact your physician and a qualified therapist to assist you in overcoming this tragically common response to loss.</p>

Criteria	Feedback
Possible major depressive episode Meet the criteria of Dysphoria and Anhedonia and exhibit mediocre symptoms of at least 2 other criteria	Your answers suggest that you could be at risk for a significant mood disturbance, even if you do not meet full criteria for a major depressive disorder. You may be struggling with some combination symptoms such as pervasive sadness, lack of energy and motivation, an inability to feel pleasure and a variety of disturbances in concentration, sleep, appetite and other domains. At its worst, you may even question your own worth, experience acute guilt and self-blame, or feel that life is not worth living. However, there are several effective forms of treatment for depression, and you are encouraged to contact your physician and a qualified therapist to assist you in overcoming this tragically common response to loss.
Subthreshold depression symptoms Score at least 16 but do not meet the above criteria	Although you do not meet criteria for depressive disorder, your answers suggest that you may nonetheless struggle with symptoms of a depressed mood, such as lack of motivation or ability to concentrate, or general discouragement and self-criticism, or inability to experience pleasure. You could also find that the quality of your sleep has eroded, or that you have lost an interest in eating. If you find that you have trouble shaking off the sadness, you might consider talking about your feelings next time when you meet with your health care professional. Bereaved people who feel like you do also benefit from participating in mutual support groups with other grieving people to feel less alone, and to share practical advice and encouragement about dealing with the loss and returning to a life that has meaning and purpose.
No clinical significance Score less than 16, not including 16	Despite the unfortunate loss of your loved one, you seem to be coping well emotionally, managing the feelings that follow from the death without succumbing to depression, or experiencing an erosion of the quality of your life. You seem able to experience a sense of purpose and pleasure as well as self-worth, and realistically look toward a hopeful future.

*PCL-C for diagnosing Posttraumatic Stress Disorder.* The diagnose of PTSD can be acquired by adding the score or checking if the result meets the criteria defined by DSM-V [48]. PCL-C also has a defined cutting point (score above 45) and the diagnostic criteria for individuals who developed PTSD [238]. The minimum score to meet the diagnostic criteria of PTSD is lower than the cutting point, so this group is added below the high score group. The feedback and criteria are described in table 5.4.

Table 5.4 The grouping criteria and feedback of PCL-C

Criteria	Feedback
Meet the criteria for PTSD score above 45 or meet the DSM-V criteria	Your score of X indicates that you could be experiencing unusually intense stress following the trauma, which can accompany the death of a loved one, especially to violent causes such as fatal accidents, natural disaster, homicide or suicide. The risk of intense stress increases if you yourself were exposed to danger, but can also be provoked by the death of another, even if you were not very emotionally close. The stress-related symptoms include fear-based re-experiencing or flashbacks, anxious arousal and reactive symptoms such as outbursts of anger, or dissociative symptoms in which people feel out of touch with reality. The unusual level of stress can also erode the quality of sleep, and increase dependence on substances, including alcohol. Because this is a serious condition, it is wise to consult a skilled therapist who is familiar with specific treatments for psychological trauma.
Score below PTSD cutting point despite meeting the criteria of DSM-V score between 36-44 but meet the criteria of DSM-V	Although you show some symptoms of heightened stress following the trauma, which often accompany the death of a loved one, especially to violent causes such as fatal accidents, natural disaster, homicide or suicide, your score of X is lower than usually reported by people diagnosed with a formal disorder. Nonetheless, symptoms of fear-based re-experiencing or flashbacks, anxious arousal and reactive symptoms such as outbursts of anger, or dissociative symptoms in which people feel out of touch with reality, can be very disturbing. They can also erode the quality of sleep, and increase dependence on substances, including alcohol. If you feel distressed by such symptoms, it could be wise to consult a skilled therapist who is familiar with specific treatments for psychological trauma.
Unlikely to have PTSD score below 35	Your score X indicates that you do not suffer from intense stress, although this condition can sometimes follow exposure to the death of a loved one. You seem to be coping with the stressors of bereavement without significant symptoms of fear-based re-experiencing or flashbacks, anxious arousal and reactive symptoms such as outbursts of anger, or dissociative symptoms in which people feel out of touch with reality. Depending on your responses to the scales measuring prolonged grief disorder or depression, however, you still might suffer from other bereavement reactions that merit attention.

*CD-RISC-10 for measuring resilience.* CD-RISC-10 was purchased from the researcher, and there was a manual providing instruction of the scoring method and the mean scores from various types of population. There are around four studies about different populations in USA [242-245], and the mean score of a national random digit dial sample is 32.1 (SD 5.8) [242]. The cut-off score was based on the mean of the national sample, we then deduct the number with one standard deviation to define the average resilience group. The low resilience group was defined as the score that is lower than the average resilience group.

Table 5.5 The grouping criteria and feedback of CD-RISC-10

Criteria	Feedback
High resilience Score above 32	Your score of X places you in the range of higher resilience. This result suggests that you exhibit a strong tendency to bounce back in the long run as a result of the way you cope with difficult life events. Your personal optimism and adaptive attitude could be a resource for both you and others as you encounter adversity and find a way to restore your equilibrium.
Average resilience Score 26-31	Your score of X places you in the range of average resilience. This suggests that you are able to adapt to challenging life conditions and ultimately regain emotional equilibrium after a certain period of coping. Like most people who feel the pain of losing a loved one, you seem to have the capacity to recover a sense of hope and optimism, and to restore a sense of balance and effectiveness over time after a major setback. Sharing the struggle with others who care about you often can help reinforce resilience.
Below average resilience Score below 25	Your score of X places you in the range of lower resilience, meaning that you may struggle with some sense of hopelessness or discouragement about major adversities, and have a hard time finding your balance again after a difficult setback. If you find that this describes your general response to very stressful life events, then this could compromise your ability to respond adaptively in bereavement. In such a case, it could be wise to consult a counselor or therapist who could help you develop the skills to cope with this hard transition, and build a foundation of resilience that can help you regain your equilibrium following this loss.

*ISLES-SF for post-loss meaning making ability.* We took a reference of SD and mean from the study about treating bereavement and loss, which suggests an after-treatment mean of 54.53(14.63) for ISLES score (the original version of ISLES-SF) [246]. The highest cut-off point was calculated by adding one standard deviation above the mean, which makes the score between 53 to 69 the range for average ability to make meaning post-loss. Since the short form of ISLES is used in the study, this score was then converted to the ISLES-SF score. For ISLES-SF, the average score should be between 21 to 26. The detailed criteria and feedback are listed in Table 5.6.

Table 5.6 The grouping criteria and feedback of ISLES-SF

Criteria	Feedback
Higher ability to find meaning post-loss Score above and include 27	Your score of X places you in the higher range of ability to make sense of your loss. This suggests that you have found ways to personally make sense of this loss and retain a sense of security in the world despite the loss. Your access to sustaining beliefs and solid sense of purpose in life and self-identity contribute to your ability to retain your footing in the world even during difficult transitions like this one.

Criteria	Feedback
Average ability to find meaning post-loss Score between 21 to 26	Your score of X places you in the normal range of ability to make sense of your loss. This suggests that you could experience a temporary challenge to your worldview or long held beliefs, but that you can gradually accommodate this impact and comprehend its meaning in your life. The ability to reconstruct meaning after a significant loss is crucial for successfully appreciating its legacy, and even growing through it.
Difficulty finding meaning post-loss Score below and include 20	Your score of X places you in the lower range of ability to make sense of your loss. You could be experiencing a significant struggle to understand why your loved one died and confusion over the significance of this loss for your life. At its worst, you might feel that the death was traumatic or unjust, and might feel insecure about who you are or where to turn in its aftermath. If this is the case, you could consider speaking with a counselor or therapist who can help you sift through the experience and come to better terms with it, in order to figure out how to move forward adaptively in your life.

*PTGI for Posttraumatic Growth experiences.* PTGI is a popular instrument measuring five areas of posttraumatic growth experiences. It does not have diagnosis function. The feedback was drafted based on the paper published by Tedeschi and Calhoun (1996).

Table 5.7 The grouping criteria and feedback of PTGI

Criteria	No criteria
Feedback	Display a histogram of each score and allow users to check their scores]  The total score of on your posttraumatic growth questionnaire is X, reflecting the degree to which you perceive yourself to have grown in one or more ways as a result of experiencing this loss. In the above bar graph you can see which areas show the greatest and least growth for you at this point in your effort to adapt to your loved one's death. Although there are no standard scores to compare your responses against, you can see your relative strengths by comparing the length of each bar, recognizing that longer bars mean greater growth in that domain.  (I) Relating to others  This score measures a deepening of your relationships with others, as reflected in greater willingness to reach out for social support, offer similar support for other people, or disclose your emotions and vulnerability to them. People who score high on this scale tend to show a growth in compassion for the suffering of others, display greater altruism, and give greater priority to people and relationships as opposed to material values.  (II) New possibilities

Criteria	No criteria
	<p>With the ending of one person's life, our lives sometimes begin again in a way that is necessarily different. By embracing the choices that life now offers them, people who score high on this scale report developing new interests or a new focus in life in a way that enriches living rather than only reduces it. If you scored high on this scale, you could be exploring new projects, new hobbies, or new opportunities. Your life path may differ from what you have planned before, and you are more motivated to make changes in the direction of things that have ultimate meaning.</p> <p>(III) Personal strength</p> <p>Individuals who score high on this scale have confronted their loss in a way that promotes their emotional growth or an enhanced self-competence. If this describes you, you could feel more self-assured and confident in addressing future losses. A sense of increased personal strength could also generalize to other challenging situations, making you more resilient and self-assertive in facing life's inevitable stressors.</p> <p>(IV) Spiritual growth</p> <p>People differ greatly in their spiritual or philosophic beliefs, as well as how these same beliefs change following a tragic or traumatic life experience. While a spiritual belief can be temporarily challenged by trauma, individuals who struggle to find meaning in the event often experience a strengthening of their spiritual grounding in life, which could lead to greater sense of control, intimacy, and purpose. This scale reflects the degree of such growth.</p> <p>(V) Appreciation of life</p> <p>A high score on this scale implies that you are better able to appreciate the preciousness of life, prioritize what is important and live life to the fullest. Having confronted sorrow, you also have deepened your capacity for joy and engagement, and "seize the day" to make moments count.</p>

5.1.2 The functionality of GIFT

Study participants can view, send, download and print their personalized feedback during or after they complete the study. It is considered a “gift” for our study participants. The app starts providing feedback to the participants in the Monitor My Grief section, so it would sustain participants interested and ease their stress in answering many bereavement-related questionnaires. It is also adherent to the ethical considerations since participants might exhibit severe bereavement or mental health concerns, and the researchers would not have a direct contact to the participants due to the anonymity of the data collection procedure. Participants could receive a certain level of supportive message or information to seek professional psychotherapist through feedback. We then added a further page to enable a complete overview of the feedback and interact with it.

However, since we do not expect study participants to revisit the profiles after participating in the study, the login function is altered. Users no longer need to create a profile with username and password. On the other hand, study participants are required to enter their email address on the registration page and receive their login link through email. After clicking on the login link, participants will create their profile in the database and can start answering the questionnaires. GIFT only creates a new user profile when the participant clicks on the personal login link, meaning users who provide a fake email address or who do not click on the personal login link will not create their profiles in the database. It allows the researcher to analyze the complete rate more precisely. Other features such as changing the display name, modifying password and email, or contacting the system administrator are temporarily disabled.

Some of the functions are necessary for administering a study on the internet. For instance, the informed consent form needs to be distributed digitally. There should be a function to automatically check frequent mistakes participants could conduct in answering a questionnaire. In the case that we pay the participants for the study, we would like to verify if participants complete all of the surveys, so a validation code should be added at the end that allows participants to report their completion. The protocol analysis has shown a lot of potential emotion triggering moments, and the IRB required that some supportive resources (links or information) should be added. Below we describe the newly added functions that enable GIFT to be implemented as a robust online data gathering system and self-monitoring tool at the same time.

*Personalizing option and the default value.* To engage the users, GIFT implements the first name of the deceased in the questions. It also helps us to avoid collecting identifiable data from the users, which could trigger ethical concerns. Users are given an additional option to leave the input field blank, and the default value will be “the lost person” or “the deceased.” We intentionally avoided using “the loved one” or “the deceased loved one” since it might not apply to all types of relationships and could cause annoyance to the users. We contacted the developers of BRISQ to receive their consent on replacing “the loved one” into the first name of the deceased or “the deceased.”

*Digitally signed informed consent form.* Although participants of the study should remain anonymous to the researchers, the study still requires the participants’ consent and the informed consent form signed by the participants should be stored in a locked and secure location by the researchers. In the case of this study, the informed consent forms should be converted into pdf files and stored in a password encrypted hard drive. The system should allow participants to read, agree with the terms of study and sign the informed consent form with as minimum information provided as possible. Therefore, we designed a single page that enables users to enter their email



address and click on the checkbox to indicate that they agree to participate in this study. After users enter their email address, the time and the email address will be added to the informed consent form. Users will be able to receive a copy of informed consent form in pdf format by email, or they can review the terms of study from the app. The database will store and encode all the informed consent forms in base64 codes so the researcher will have the same files.

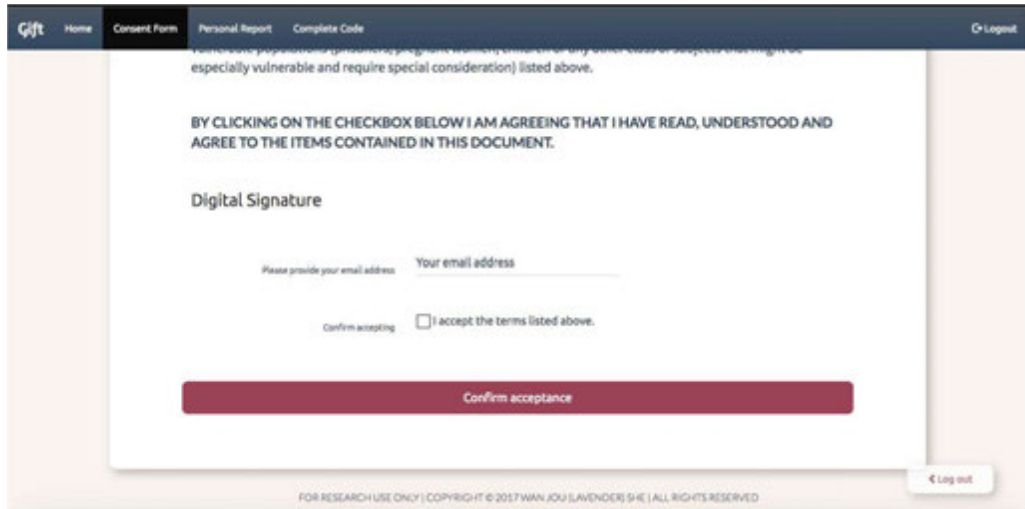


Figure 5.2 The digital signature of informed consent form

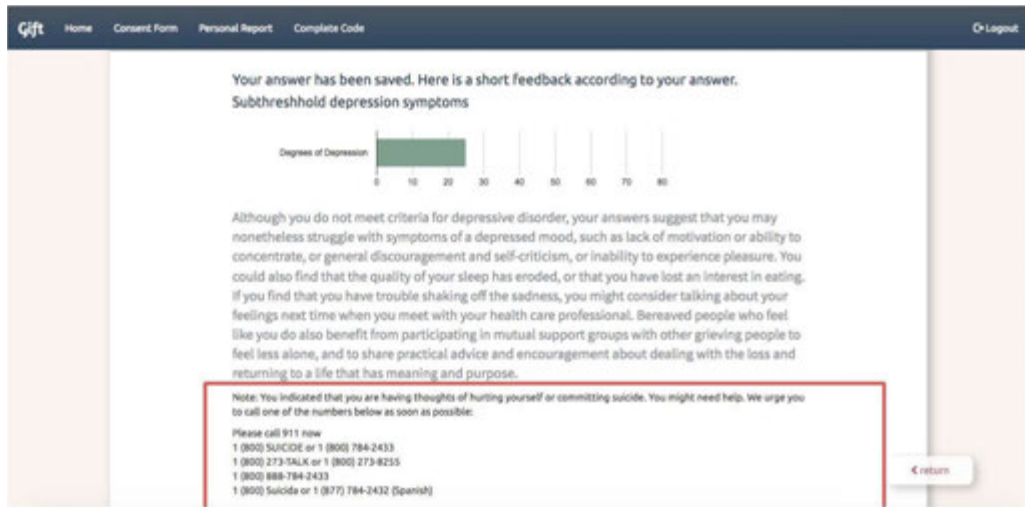


Figure 5.3 Displaying the suicidal hotline

Add suicidal hotlines for individuals who exhibit suicidal or self-hurting ideations. At least

two of the questionnaires in GIFT, BRISQ, and CESD-R inquire about the suicidal ideation. Disregarding whether the questions investigate about the suicidal ideation in the past week, month or further in the past, it is the designers' responsibility to be highly cautious about administering these kinds of questionnaires. The suicidal hotlines for different countries can be found through suicidal.org, which is a non-profit organization that collects most of the hotlines that offer counseling services for individuals with suicidal ideations [247]. It is not possible to directly copy-paste the suicidal hotlines due to copyright issue, but it is possible to direct the users who exhibit suicidal ideations to the page that displays the suicidal hotline of their countries. In GIFT, the users are expected to complete the personal information questionnaire first before proceeding to the other questionnaires, and the system will store the users' country of residence to connect to the relevant hotlines. The criteria of displaying additional suicidal hotline in the feedback are based on the answer to question 14 (I wished I were dead) and 15 (I wanted to hurt myself) in CESD-R. If the user's answer is more than 1 day in the past 2 weeks, the suicidal hotline will be displayed at the bottom of the feedback.

*Attention checkers in the questionnaire.* Since GIFT will be implemented as a data collection instrument, it is of imperative importance to ensure users provide precise data. According to the participants from the protocol study, bereaved users could experience difficulty in concentrating or memorizing what they did a couple of minutes ago. Usually, attention checkers are often designed as questions in a questionnaire and indicate the user to select the answer that seems impossible to be chosen if the user does not pay attention [248]. It would not be suitable for bereaved users since they could be annoyed and confused easily. Based on testing the app with colleagues, we also noticed some mistakes that were frequently made by even normal users. We decide to place a reminder under the question after the user selects the answer that might not make sense for the researchers.

Table 5.8 displays a list of attention checkers we have programmed. Despite how conflicting the mistakes seem, these are frequently observed errors when the researcher exams the result of the questionnaires. Whenever the users make a mistake in a question, the attention checker will be activated, and the background of the question will turn red, the font of the question bold and the attention checker message display at the bottom of the question (see Figure 5.4). The message will repeat the user's selection and indicate where a user could find reference to check the answer. For instance, "Attention: The deceased died before you were born. This answer can fail you in the attention check. Please double check your answer to question 2 or this question." Table 5.8 List of attention checkers and the criteria



Attention checkers	Criteria
Age of the user	User's age being younger than 18 years old
Gender of the user	User being a mother or father or any other senior figure to the deceased while his/her age is younger.
	User being a female while being a father/grandfather/uncle/brother of the deceased
When did the loved one die	User being male while being a mother/grandmother/aunt/sister of the deceased
	The loved one died 5 years ago, the user does not qualify to participate in the study
Age of the deceased	The loved one died before the user was born (user age younger than the year the loved one died)
	The age of the deceased is younger than the user while being a mother/father/grandmother/grandfather/uncle/aunt of the user
Time knowing the deceased	The age of the deceased is older than the user while being a son/daughter of the user
	User's age is younger than the duration he/she knows the deceased

*Save the data in the progress.* Almost all of the participants in the protocol analysis have indicated that they would appreciate the function of saving their current progress and revisit where they left off whenever they feel like. It is critical to keeping the data whenever a user clicks on the answer. Users should also be allowed to review their response when they enter the questionnaire page again. GIFT stores users' entry by creating an event listener for user's each question answer. It also stores two-time stamps. The first timestamp is saved when a user first visits the questionnaire, and the second timestamp is updated whenever the user indicates a new answer or submits the questionnaire. It allows the researcher to track how long a user takes to complete a session and use the data for further analysis.

The app also explicitly thanks the user each time when the user completes a questionnaire and confirms that the data has been saved (See Figure 5.5 for example).

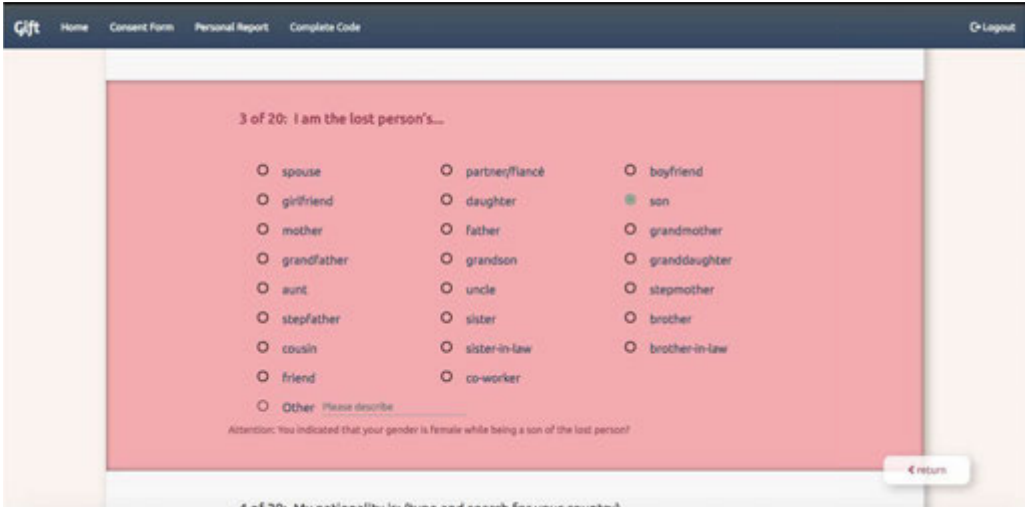


Figure 5.4 Warning from the attention checker

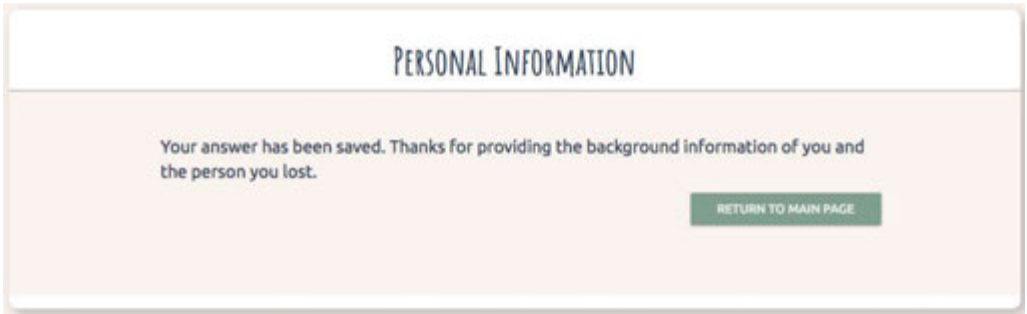


Figure 5.5 Acknowledge the completion

*Provide visual feedback of the questionnaire result.* A visual bar chart was added in the result page to provide straightforward feedback of the questionnaire result. The bar chart should indicate the highest and the lowest score of the questionnaire and where the user's score falls on this scale (see Figure 5.6).

If the questionnaire is measuring multiple factors, the visual feedback will provide an excellent reference for comparing between each factor (see Figure 5.7).

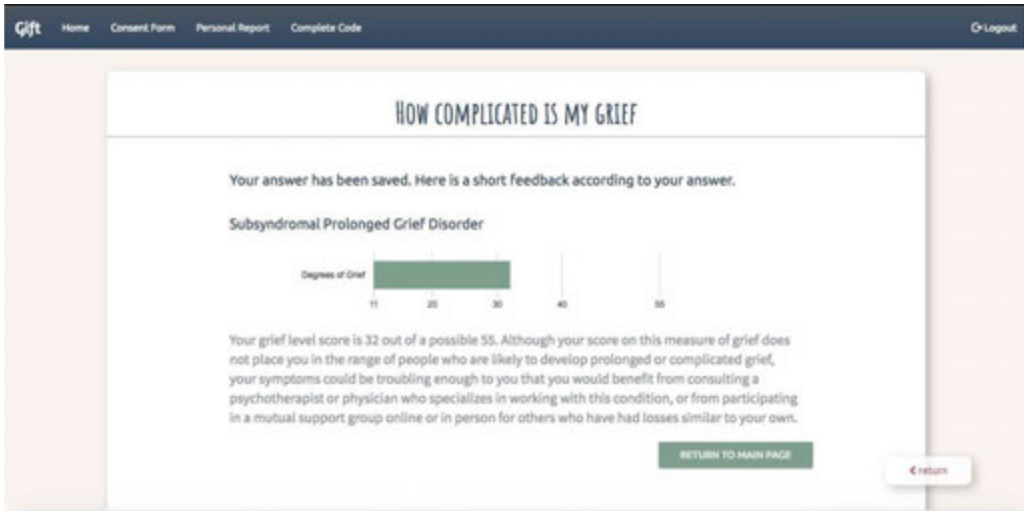


Figure 5.6 The visual feedback of the score

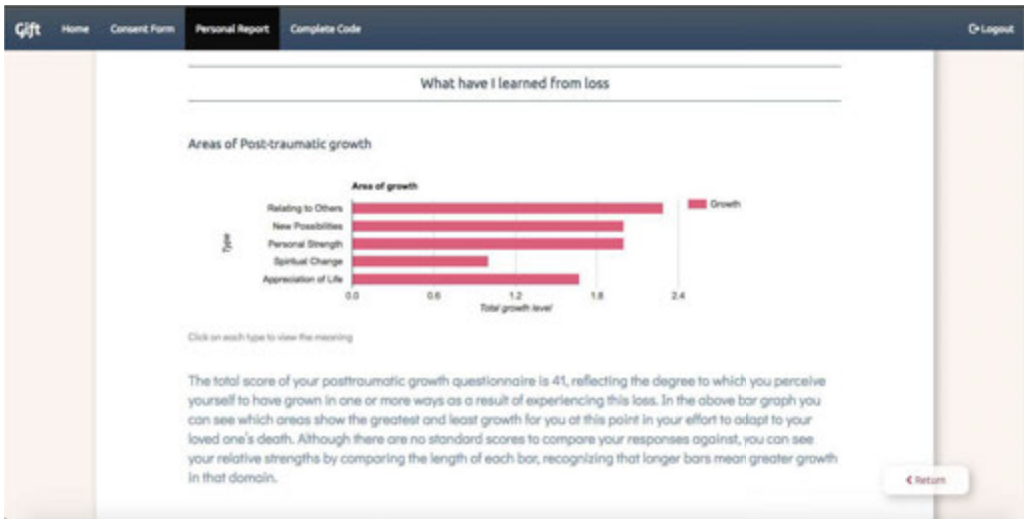


Figure 5.7 The visual feedback of multiple scores

*Keep a track of user's change on the questionnaire answer.* The protocol analysis shows that user might visit the questionnaire for more than once to check or modify their answers. In general, GIFT should allow users to alter their responses in case they believe they have made a mistake, but in the study, it could generate confusion and conflicts in analyzing the data. We decided to keep each modification as a new entry for the questionnaires in the Basic Information section only since these surveys mainly inquire the users' socio-demographic information and

the bereavement-related characteristics. These types of information do not easily change due to users' psychological states or emotion, and it would be more convincing that users would revisit the questionnaire simply because the information they provided before was wrong. Users would not be able to change their answers of the questionnaires in the Monitor My Grief section but will be presented the feedback instead.

If a user visits the questionnaire in the Basic Information again and decides to change his/her answer to a question, the system makes a new entry and keep the old data intact. With this concern in mind, GIFT will display users' answers when they visit the page again, and in case users make any changes on the questionnaire, the system will create a new entry with the modified change. The principle is to analyze the data base on the latest entry. The benefit of keeping a track on users' modifications is that the change could provide valuable insights for further analysis, and the researcher would have a chance to determine which version to use in the analysis.

*Add completion code for participants who will receive compensation after the study.* GIFT will be deployed through internet and participants will receive compensation after completing the study, so a function to confirm if participants complete all of the questionnaires is necessary (inspired by the completion code of Qualtric) [248]. We add a link to the app which is only accessible after participants complete all the questionnaires. Participants who will receive a compensation should generate a completion code through the link. Once the code is generated, it is stored in the MySQL database with a foreign key linked to the user's profile and GIFT will send an email with the completion key and participant's login link to the system admin. Upon receiving the email, the system admin, in this case, the researcher, will be able to compare the completion code stored in the database with the one reported by the participant. If both codes match, it is proof that a participant has completed the study.

*Check the quality of the answer by the duration of the study.* The pilot test of the app indicated that the quality of answer could significantly reduce if a participant spent less than 15 minutes in completing the nine questionnaires. Most of the pilot testers, including the fellow researchers, took around 23 to 26 minutes to complete the study. If we are to deploy GIFT on the internet, there should be various strategies to prevent poor answers. We further programmed an admin page to check the completion time of each questionnaire and the whole study. When a participant completes the study, the system admin can check the duration based on the completion code reported by the participant. If the duration is less than 15 minutes, the system admin should first examine if the attention checkers have been activated and should consider carefully when including the answer.

5.1.3 The Navigation of GIFT

GIFT consists of nine questionnaires, and a majority of the dependent and independent variables are measured by four questionnaires, Personal Information, BRISQ, CGRF and PG-13. In other words, even if a user failed to complete all of the questionnaires, the data will still be worth analyzing if he/she at least completed these four questionnaires. Therefore, the four questionnaires will be prioritized in the design of the navigation interface. Some of the significant changes of GIFT navigation interface are described below.

*Vertical layout with accordion menu.* We realized that participants who used a mobile device naturally went from top to the bottom and had experienced less difficulty in going to the next questionnaire after completing one. Since the navigation design of GIFT will mainly focus on nudging users to complete all the questionnaires at the current stage, we changed the layout into a vertical layout with the accordion menu. Surveys from each section are grouped (see Figure 5.8).

We prioritized the essential questionnaires on top, and the rest are naturally placed below them. In this way, we wish to emphasize on collecting the minimum data for analysis knowing that participants might choose to drop out in the middle of the study. The information that will be used to personalize the phrasing of questions in the following questionnaires will be asked in Step 1 Personalize. In this case, we implement the first name and gender of the deceased, so the relevant questions are asked at the very beginning.

The lesson learned from the protocol analysis was that participants often almost ignored the introduction of the questionnaire if the information was placed on the same layer. Therefore, the display of questionnaire title, introductions and instructions of answering should be layered. The accordion menu was used to enhance the awareness that an extra layer of information will be displayed after participants click on the questionnaire title, and before participants click on the start questionnaire button (see Figure 5.9). Participants strongly appreciated having a gauge of the duration of the questionnaire, since it helped them to assess how much time they should commit to the questionnaire and will increase their patience in the session.

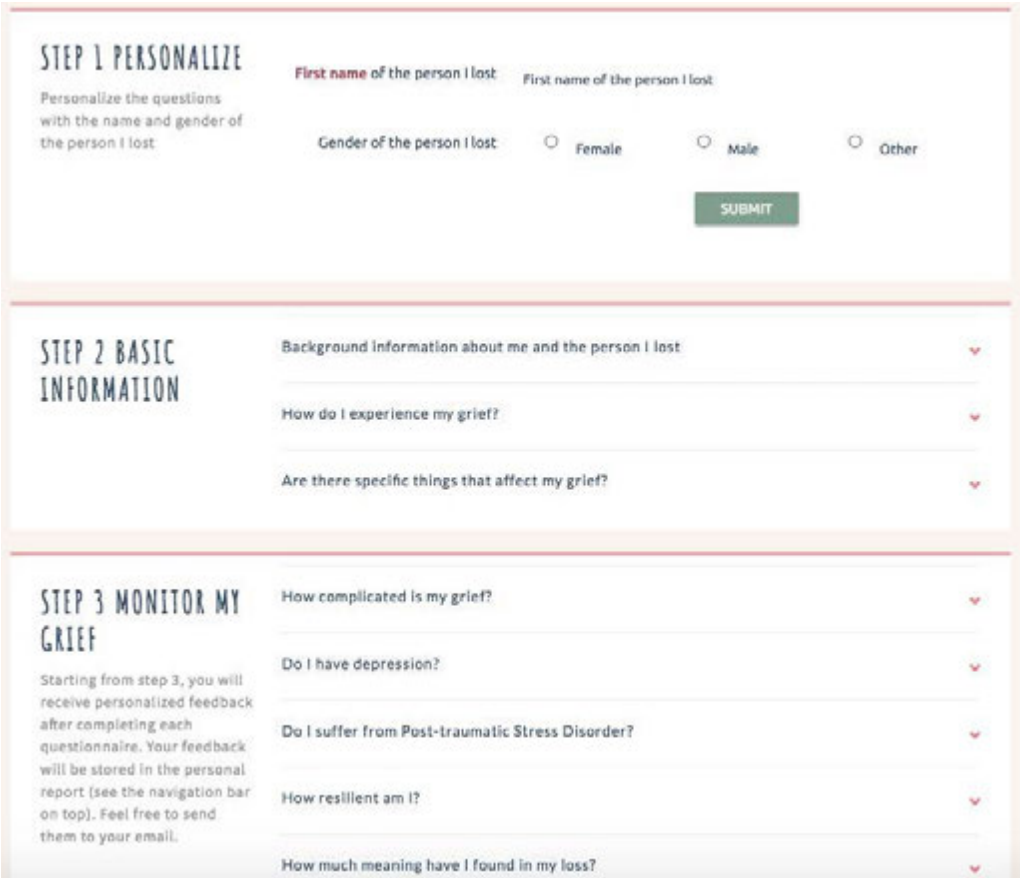


Figure 5.8 The vertical layout of GIFT interface

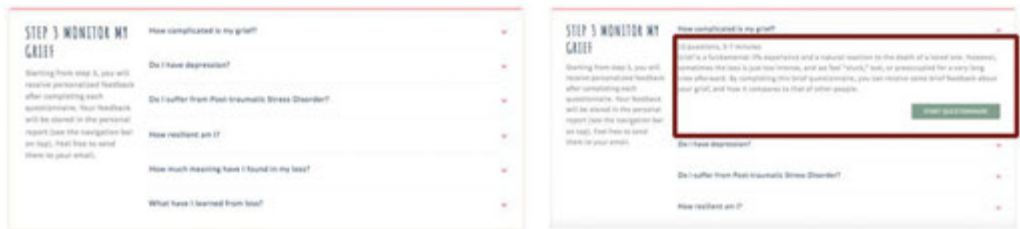


Figure 5.9 Accordion menu

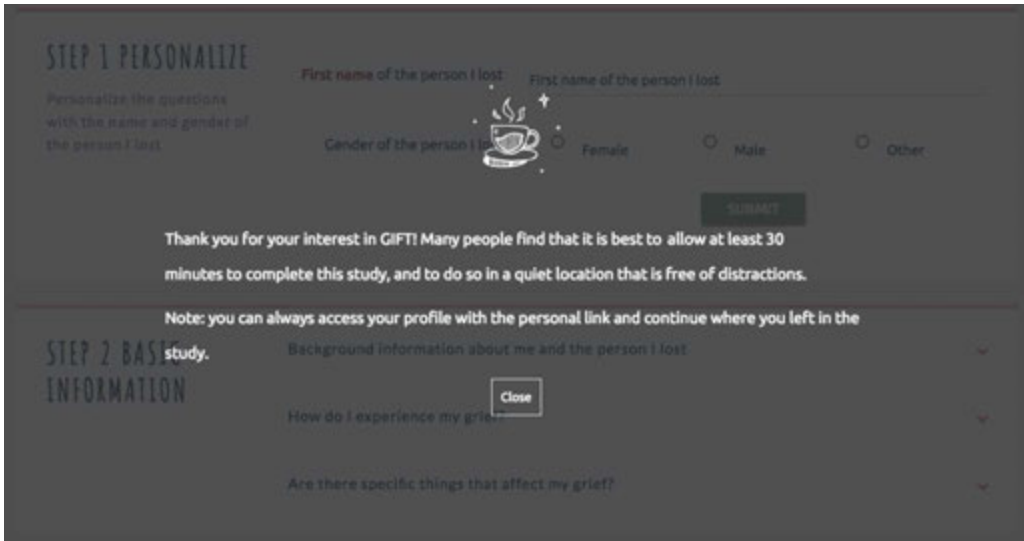


Figure 5.10 Welcoming message at the beginning of the study

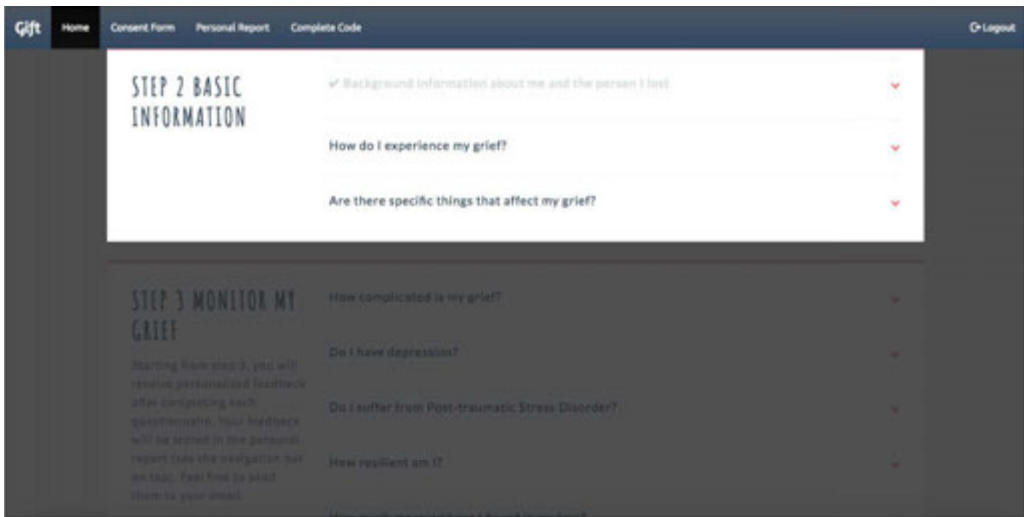


Figure 5.11 The navigation between scales

Provide instructions for the user when he/she first enters the main page or questionnaire. The welcoming message should let users know what to expect in the app. At the first login to the app, GIFT displays a welcoming message that gives a general gauge of the duration of the study, suggests the environment suitable for taking the study and informs users that they can access the profile even if they decide to take a break and close the page. The complete message is “Thank you

for your interest in GIFT! Many people find that it is best to allow at least 30 minutes to complete this study, and to do so in a quiet location that is free of distractions. Note: you can always access your profile with the personal link and continue where you left in the study.”

Scroll to the next questionnaire. It is demotivating if the system simply redirects the user back to the main page without indicating which questionnaire to visit next. We utilized the scroll script to automatically direct to the next questionnaire and reduce the saturation of the font color of the previous questionnaire. This design acknowledges the completion of the previous questionnaire and naturally reminds the user that there are questionnaires uncompleted (see Figure 5.11).

Scroll to the skipped questions. Researchers should try to reduce the missing values in a questionnaire and attempt to persuade participants to give thoughts to all of the questions. Although participants answers are stored on the progress of completing the questionnaire, the system will only recognize the completion of a questionnaire after the participants answer all of the mandatory questions. In GIFT, the system implemented a pop-up window to inform participants how many questions were left unanswered in the questionnaire. It severely annoyed the participants, and some participants did not realize that it was a warning message and got confused when they could not submit the answer. To prevent it, GIFT implemented the scrolltop function from jQuery to directly scroll to the questions that are unanswered. If a user skips several questions and tries to submit a questionnaire, the system will then directly scroll to the first question that is uncompleted and change all the background color into light red for the uncompleted questions. The background color of the unanswered questions will remain light red if a user fails to indicate an answer and will change back to white if an answer is indicated.

Instruction of how to interact with the slider. The Likert Scale items are placed horizontally on a slider. The default location of the handle is in the middle of the answer (see figure, the default location of the handle is on Neither agree nor disagree). However, since participants could scroll down and ignore the question, GIFT would not recognize the answer if users did not click on the handle. We made it explicit by giving an instruction at the beginning of the questionnaire and also changing the color on the handle when users answer. A tooltip box is displayed with the item selected when users hover over the option.

5.1.4 Preparing to deploy GIFT on the Internet

Although most of the participants from protocol analysis did not concern the online data security, the IRB required to safeguard the data transmission security and prevent the potential data breach. It is also worth noting that the participants should be de-identified in the study as much as possible, which means that the investigators of the study should not be able to identify the participants given the data they gathered from the participants. The best situation



is to collect opinions from the participants without asking any Sensitive Personal Information (SPI) or Personally Identifiable Information (PII). Examples of SPI are the full name of the participant or the home address of the participant. GIFT creates a primary key in the database to link the answers to all the questionnaires from a single user. Under the supervision of the IRB, we asked the participants to provide only the email address and encrypted the user profile with Advanced Encryption Standard 128 (AES) method [249]. The reason for providing email address was to send the personal login link and feedback to the participants. Participants will not provide their names, usernames or passwords. A Secure Socket Layer (SSL) certificate was also purchased and installed on the website to ensure the security of data transmission.

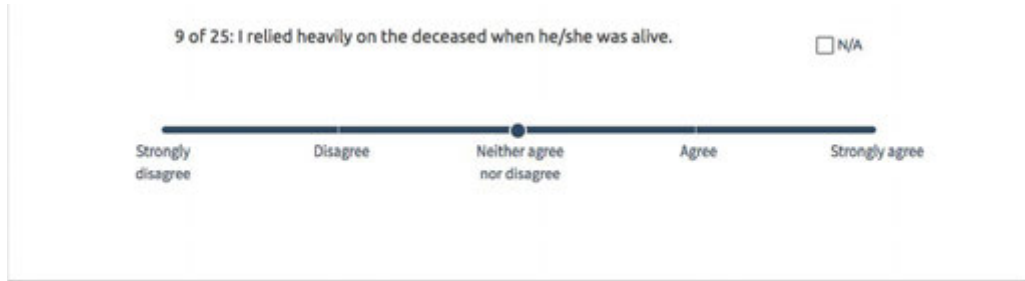


Figure 5.12 The slider design for Likert Scale items



Figure 5.13 The responses when participant hovers and clicks on the slider

5.2 Studying Method

5.2.1 Ethical consideration

The study participants were invited to interact with GIFT through computers or mobile devices. The study protocol was reviewed and approved by the Institutional Review Boards from both the Eindhoven University of Technology (under the case number Archie 533) and the University of Memphis (PRO-FY2017-286).

5.2.2 Deployment of GIFT DG and data collection

Participants were asked to complete nine questionnaires, the data from which was de-identified before analysis. A foreign key was created as a reference between different tables in the database and remain the capability to identify the answers from the same participant. Amazon’s Mechanical Turk (Mturk) was selected as the primary portal for data collection, and the following exclusion criteria were utilized to exclude the disqualified bereaved participants.

- Participants who are under 18 years old
- Participants who belong to one of these vulnerable populations: prisoner, pregnant woman, child or any other class of subjects that might be especially vulnerable and require special consideration
- Participants who are not grieving the death of a loved one
- Participants who loved one died less than 6 months ago
- Participants whose loved one died over 5 years ago
- Participants who cannot read English well

Participants received \$1.5 in compensation for their contribution. Studies show that Mturk is an alternative portal that helps researchers to gather low-cost yet high-quality data from diverse samples of participants, making it a relatively affordable and reasonable choice for this exploratory study [250, 251]. Therefore, the bereaved samples we collected from the Mturk were expected to be generalizable to the population.

5.2.3 Data extraction

The raw data entries were stored and encrypted in MySQL database. We selectively extracted 611 rows of data from the database. Email addresses were not extracted or decrypted. Each data entry was assigned a unique ID number associated with the original data, which was entered in SPSS for further analysis.



### 5.2.4 Analysis

To infer the variation of the dependent variable and evaluate the contribution of each independent variable, we adopted regression analysis. It was difficult to merely utilize PG-13 score as a dependent variable because the diagnosis required “yes” on two more questions (#3 and #13). In the end, we had to use PGD diagnosis as a binomial variable. Logistic regression is a robust analysis method widely adopted in many classification studies that aim to predict the membership of the binomial or ordinal dependent variable (in this case, we used binary logistic regression) [252, 253]. The aim of the analysis was to find a model that best describes the data given the minimum number of variables included (parsimony). Five different steps were conducted to (1) prepare the data, (2) purposefully select the variables, (3) fit the multivariate model, (4) examine the assumptions and then (5) assess the performance of the model. Below we explain how these steps were conducted.

#### *Step one: preparing the data for analysis with necessary correction and splitting*

We checked the data to avoid incomplete information in the variables by using the contingency tables to check if the data collected could fulfil all the possible combinations of the categorical variables. We then compared the proportion of PGD griever in this sample to the theoretical proportion in Lundorff et al.'s study (2017) [51], which reported the prevalence of PGD to be 9.8% among the grieving population. The prevalence of PGD in our study was 4.9%, which was completely represented by the Mturk participants. However, it would result in PGD participants being under represented in the analysis process. Given that ignoring the theoretical prevalence of an event could sharply underestimate the probability of rare events [254], we weight the data to compensate the difference between the PGD fraction in the sample and the population [254]. Given the population fraction and the sample fraction. The weight of the probability that the event will happen is  $\bar{y}$ , and the weight of the probability that the event will not happen is  $\omega_1 = \frac{\tau}{\bar{y}}$ . The weight variable  $\omega_0 = \frac{(1 - \tau)}{(1 - \bar{y})}$  was calculated with the following equation, which gave a weight of 0.94 to the normally grieving participants and 2 to the PGD participants.

$$\omega_i = \omega_1 Y_i + \omega_0 (1 - Y_i)$$

After weighing the data, we randomly split the sample into two groups that contained respectively 60% and 40% of the data for fitting the model and cross-validating the model. The distribution of gender, age, type of loss, employment status, and relationship to the deceased was checked before the analysis was performed to make sure all the groups contained enough samples to perform the analysis.

#### *Step two: purposefully selecting the variables through univariate logistic regression*

Several univariate Logistic Regressions were conducted to extract the predictors that exhibit potential predictability (at the significance level of p-value > .25 and 95% confidence interval) of the membership of normal and PGD griever [255, 256]. The purpose of using a cut-off level of .25 instead of the traditional significance level was to avoid ignoring potentially essential variables for the multivariate analysis, which can be justified by literature [257, 258].

#### *Step three: fit the multivariate logistic regression model*

Pearson's Correlation Coefficient was performed to investigate and remove the highly correlated items. The model was fitted with the variables extracted from step two with 60% of the participant's data. In this process, we adopted Backward Likelihood Ratio (LR) stepwise method to find the best model that described the data since this study aimed to explore the variables and Backward LR was preferable [253, 259, 260]. Gender and age were always included in the multivariate logistic regression analyses disregarding whether they were significant in the univariate analysis because the study was still at a stage of exploring the best variables. The interaction between variables that demonstrated theoretical values should also be considered in the analysis (e.g., post-loss perceived financial difficulty with unemployment status).

#### *Step four: examine the independence, linearity and collinearity*

Most of the assumptions were checked in the data preparation phase such as correlation and frequencies of variable combinations. At this step, we were only interested in the variables that contributed to the model and had to ensure these variables did not violate the assumptions or perform necessary transformations. Linearity between continuous variables and the dependent variable was tested by inputting the continuous variables and the interactions of the variables and its logarithm value into the logistic regression. Multicollinearity was examined by performing multiple linear regression in SPSS and check the tolerance (should not be < 0.1) and VIF value (should not be > 10). In the end, independence was tested by examining the overdispersion of the model with the dispersion parameter (the ratio of chi-square and degrees of freedom should not be > 2 or < 1). Goodness-of-fit was tested by checking if the Hosmer and Lemeshow value was not significant at the level 0.05 [253].

#### *Step five: assessing the model performance*

The internal validation of the model was examined by cross-validating the predicted result among the selected samples and unselected ones. The performance of the model was evaluated by the Area Under the Curve from ROC Curve.

5.3 Results

A total of 829 users requested the personal login link, and 778 signed the informed consent form but some dropped out in the middle of the study. Overall, data from 611 participants who completed mandatory measures were used in the final analyses. From this, 30 participants screened positive for PGD (i.e., were bereaved for >6 months, endorsed significant functional impairment, and scored >44 on the PG-13). In general, around 4.9% of the participants screen positive for PGD. The demographic data of the participants and the deceased loved ones was reported in section 5.3.1. The three models fitted with only background predictors, background predictors with risk factors, and background predictors with risk factors and outcome predictors were reported and compared in the following sections.

The dependent variable (PGD confirmed) were given more weight to correctly represent the probability (9.8% PGD among all the grievers) suggested by the literature review [51]. The weighted dependent variable was used in fitting the models, and the models built were cross-validated on the raw (unweighted) data. Since the probability of PGD happening is higher due to weight correction, the implication might be that risk factors would be given higher odds ratio (the further odds ratio is from one, the stronger association it has toward the dependent variable [261]) and predictive factors would be given smaller odds ratio.

5.3.1 The Socio-demographic data of study participants and the deceased

More than half of our samples were female participants (64%). The mean age was 39 years old. The details of the socio-demographic data are displayed in Table 5.9 (some continuous variables are displayed with standard deviations, referred to as SD).

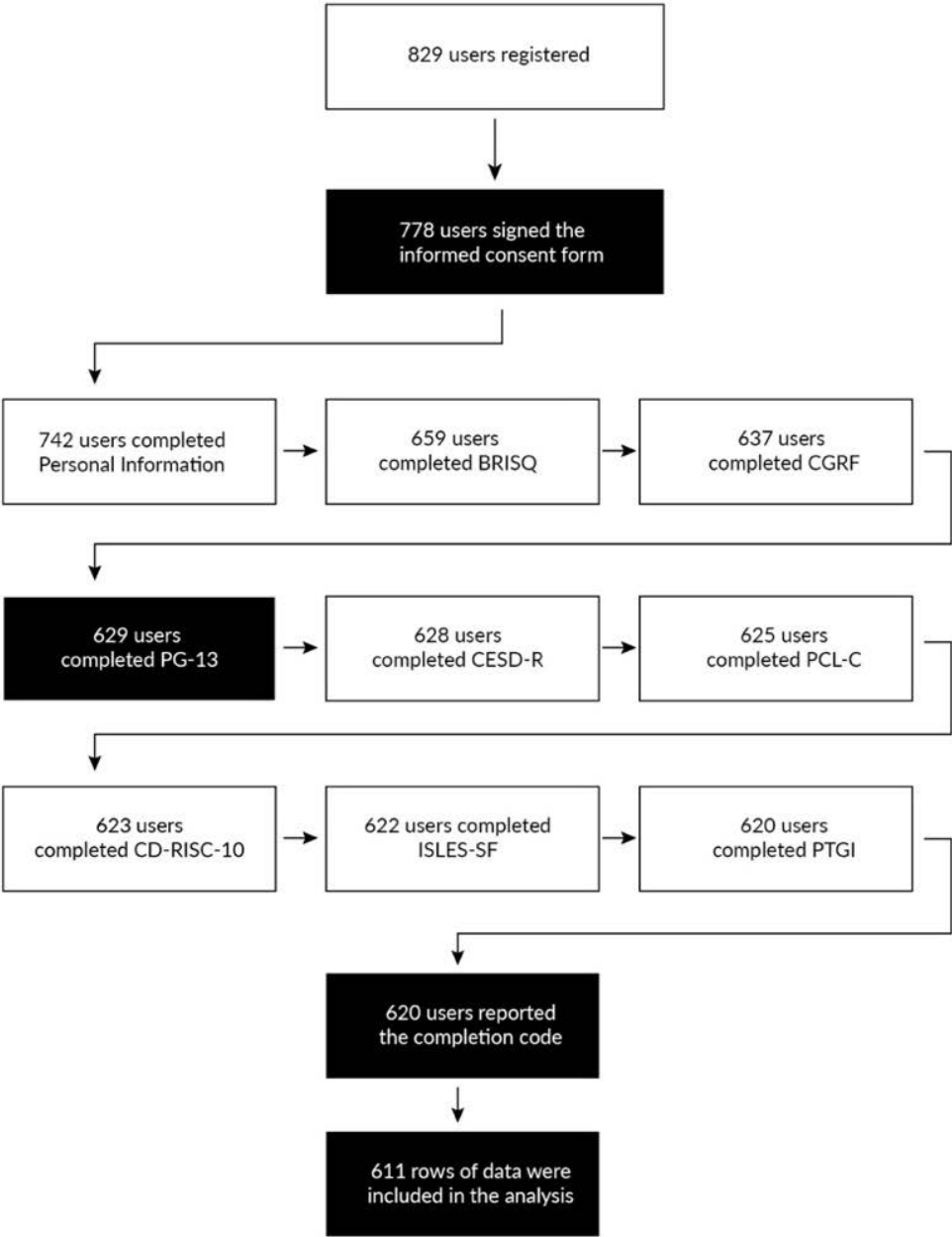


Figure 5.14 Flow of participant numbers in each stage of the study

Table 5.9 The socio-demographic characteristics of sample population (n = 611)

Participants social-demographic factors	
<b>Age in years mean (SD)</b>	38.77 (11.676)
<b>Gender</b>	
Male	222 (36.3%)
Female	389 (63.7%)
<b>Nationality</b>	
United States of America	590 (96.6%)
Other nationality	21 (3.4%)
<b>Country of residence</b>	
United States of America	605 (99%)
Outside USA	6 (1%)
<b>Relationship to the deceased</b>	
Child	156 (25.7%)
Grandchild	138 (22.6%)
Spouse or partner	79 (12.9%)
Friend or coworker	70 (11.5%)
Parent	47 (7.7%)
Relative	38 (6.2%)
Brother or sister	37 (6.1%)
Other	45 (7.4%)
<b>Marital status</b>	
Married	282 (46.2%)
Single	230 (37.6%)
Widowed	50 (8.2%)
Divorced	49 (8%)
<b>In a committed relationship</b>	
Yes	415 (67.9%)
No	196 (32.1%)

Participants social-demographic factors	
<b>Years of formal education</b>	
Less than 12 years	51 (8.3%)
13 to 16 years	394 (64.5%)
More than 17 years	166 (27.2%)
<b>Employment status</b>	
Employed full-time (greater than 30 hours per week)	414 (67.8%)
Employed part-time (less than 30 hours per week)	82 (13.4%)
Not currently employed, not looking for work	39 (6.4%)
Not currently employed, looking for work	27 (4.4%)
Full time student	12 (2%)
Other	37 (6.1%)
<b>Religion</b>	
Christianity	283 (46.3%)
Atheism	77 (12.6%)
Agnostic	56 (9.2%)
Not Applicable	55 (9%)
Catholic	39 (6.4%)
None	15 (2.5%)
Spiritual	14 (2.3%)
Buddhism	10 (1.6%)
Protestant	8 (1.3%)
Roman Catholic	7 (1.1%)
Hinduism	6 (1%)
Islam	6 (1%)
Judaism	6 (1%)
Baptist	3 (0.5%)
Jewish	2 (0.3%)
Other types of religion	24 (3.9%)

Factors related to the deceased	
<b>Age of the deceased (mean (SD))</b>	55.29 (25.80)
<b>Gender of the deceased</b>	
Male	315 (51.6%)
Female	296 (48.4%)
<b>Time since death in months (SD)</b>	25.22 (20.972)
<b>For how long did the griever know the deceased in years (SD)</b>	26.64 (15.77)
<b>Types of loss</b>	
Natural anticipated death (e.g., old age, terminal illness)	281 (46%)
Natural sudden death (e.g. heart attack, unexplained illness)	169 (27.7%)
Fatal accident (e.g., motor vehicle accident, drowning, electrocution, fall)	74 (12.1%)
Suicide	30 (4.9%)
Homicide	11 (1.8%)
Medical malpractice (e.g., wrongful death following birthing, surgery, or other procedure)	13 (2.1%)
Other	33 (5.1%)
<b>Frequency of contact with the deceased before the death</b>	
Everyday	27 (4.4%)
2-7 times per week	310 (50.7%)
Every other week	79 (12.9%)
Once per week	66 (10.8%)
Once per month	60 (9.8%)
Less often than once per month	67 (11%)

### 5.3.2 Model 1 with only background factors

The first model was fitted only with the socio-demographic factors (n=10) and factors related to the deceased (n=6). The univariate result is displayed in Table 5.10. The variables that were considered insignificant predictors in this step were griever's age, griever's gender, years of formal education, importance of spirituality, number of other loss experiences in the past three years, and how long ago the deceased died. The rest of the variables were included in the stepwise multivariate analysis, which resulted in seven variables in the model one. Model one is displayed in the table 5.11. The true positive rate of training samples was 50% but dropped to 0% for the unselected samples. It was unable to identify any PGD cases in the unselected samples, and the AUC value was 0.574 (see Table 5.20). The contingency table for the cross-validation is presented in Table 5.12.

Table 5.10 Odds ratio of background factors with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases)

Variables	N	Odds ratio (95% CI)
Socio-demographic factors of the bereaved (n = 10)		
<b>Griever age in years</b>	379	0.998 (0.970-1.027)
<b>Griever gender</b>		
Male	246	Ref
Female	133	1.004 (0.505-1.996)
<b>Relationship to the deceased</b>		
Spouse or partner	53	Ref
Child	87	0.271 (0.107-0.685)**
Parent	27	-
Grandchild	97	0.371 (0.161-0.854)*
Brother or sister	26	-
Relative	22	-
Friend or coworker	38	0.152 (0.033-0.707)
Other	28	-
<b>Bereaved spouse (binominal)</b>	53	4.652 (2.287-9.461)***
Socio-demographic factors of the bereaved (n = 10)		
<b>Marital status</b>		

Variables	N	Odds ratio (95% CI)
Single	147	Ref***
Married	165	0.497 (0.202-1.222)***
Divorced	31	1.379 (0.422-4.513)
Widowed	36	4.828 (2.068-11.271)***
<b>In a committed relationship</b>		
Yes	249	Ref
No	130	3.064 (1.564-6.000)**
<b>Employment status</b>		
Employed full-time (greater than 30 hours per week)	252	Ref
Employed part-time (less than 30 hours per week)	50	0.301 (0.070-1.301)*
Not currently employed, looking for work	20	0.776 (0.172-3.506)
Not currently employed, not looking for work	24	0.641 (0.144-2.861)
Full time student	9	-
Other	24	0.641 (0.144-2.861)
<b>Years of formal education</b>		
Less than 12 years	30	Ref
13 to 16 years	238	0.809 (0.262-2.499)
More than 17 years	111	0.660 (0.192-2.274)
<b>Frequency of religious activity</b>	379	1.098 (0.892-1.351)
<b>Importance of faith/spirituality</b>	379	0.930 (0.740-1.168)
<b>Multiple prior losses</b>	379	0.990 (0.794-1.235)
Background factors related to the deceased (n = 6)		
<b>Deceased age in years</b>	379	1.008 (0.995-1.022)*
Background factors related to the deceased (n = 6)		
<b>The deceased gender opposite to the bereaved</b>		
Same gender	187	Ref

Variables	N	Odds ratio (95% CI)
Opposite gender	191	1.868 (0.942-3.701)*
<b>Recency of death</b>	379	0.821 (0.639-1.055)
<b>Types of loss</b>		
Natural anticipated death (e.g., old age, terminal illness)	170	Ref**
Natural sudden death (e.g. heart attack, unexplained illness)	101	1.424 (0.591-3.427)
Homicide	6	13.667 (2.973-62.830)**
Suicide	20	-
Fatal accident (e.g., motor vehicle accident, drowning, electrocution, fall)	51	2.971 (1.203-7.340)*
Medical malpractice (e.g., wrongful death following birthing, surgery, or other procedure)	11	6.074 (1.612-22.885)**
Other	20	-
<b>Frequent contact with the deceased</b>	379	0.661 (0.484-0.902)**
<b>How long the grievors know the deceased</b>	379	0.992 (0.971-1.013)*
* p < .25, ** p < .01, *** p < .001 the first cut-off value of .25 is suggestive for exploring potential variables		

Table 5.11 Model 1with background factors (n=379 selected cases / 232 unselected cases)

Model 1 variables	Adjusted Odds Ratio (95% CI)
Relationship to the deceased as a spouse	9.053 (2.976-27.542)***
Relationship to the deceased as a grandchild	6.041 (1.960-18.618)**
Being in a committed relationship	6.224 (2.401-16.072)***
Cause of the death due to fatal accident	3.172 (1.170-8.603)*
Frequency of religious activity	1.199 (1.01-1.424)*
* p < .05, ** p < .01, *** p < .001	

Table 5.12 The contingency table for cross-validating the performance of Model 1



Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	
60% selected samples	PGD	5 (TP)	5 (FP)	50%
	No PGD	15 (FN)	353 (TN)	96%
Overall % correct				73%

Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	
40% crossvalidating samples	PGD	0 (TP)	6 (FP)	0%
	No PGD	10 (FN)	215 (TN)	96%
Overall % correct				48%
***TN: True Negative, TP: True Positive, FN: False Negative, FP: False Positive				

### 5.3.3 Model 2 with background factors and bereavement risk factors

We included two risk factor measurements, BRISQ and CGRF, in our study. To select variables for multivariate analysis, we performed the reliability test to examine which questionnaire had a better reliability. The reliability tests were satisfactory with BRISQ receiving 0.909 and CGRF 0.799 in Cronbach's Alpha. Hence, the data from these two questionnaires were used to fit the best model, but in case the variables were measured in both questionnaires, the data from BRISQ would be used first.

Table 5.13 presents the variables examined from both questionnaires. Some of the variables were measured by only BRISQ or CGRF. Predictors were separated into three groups: intrapersonal predictors (n=13), interpersonal predictors (n=10) and bereavement-related characteristics (n=6). The code in the bracket indicates the item number from the BRISQ or CGRF that was/were administered to measure the predictor. Some of the predictors were measured by several questions and were included as a single variable in the univariate logistic regression.

The second model was fitted with the significant predictors extracted from the univariate analysis and the significant variables from the background variables. Griever's age and the deceased's age were recoded as categorical variables to avoid causing excessively large and abnormal Odds Ratio (abbreviated with OR in the following paragraphs). The model two is presented in Table 5.14.

The confirmed risk factors suggested by the reviews but were not supported by our study were insecure attachment style, low social support, high pre-death dependency to the deceased and high neuroticism. Out of the 28 independent risk factors, seven were considered significantly correlated to PGD. Model 2 further included three background factors (age of the bereaved, being a spouse of the deceased, and the frequency of contact with the deceased pre-death).

The cross-validation result of Model 2 exhibited a significant increase of model performance. The true positive rate was 76.1% for the training samples and 44.4% for the unselected samples for Model 2. The AUC value was 0.833 with 95% percent confidence interval between 0.731 and 0.935, suggesting that Model 2 demonstrated good specificity and sensitivity.

Table 5.13 Odds ratio of bereaved-related risk factors measured respectively by BRISQ and CGRF with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases)

	Univariate regression [BRISQ]	Univariate regression [CGRF]
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Intrapersonal predictors (n = 13)		
[CG01] High neuroticism		1.669 (1.268-2.197)***
[BRISQ10][CG02] History of mental illness pre-loss (ex. Depression or adjustment disorder)	2.621 (1.813-3.788)***	1.402 (1.098-1.790)**
[CG03] Believe in therapy		1.835 (1.315-2.559)***
[CG04] Negative interpretation of the grief		3.048 (2.122-4.379)***
[CG05*CG06] Religiosity / spirituality		1.009 (0.964-1.057)
[BRISQ24][CG07] Economic decline / financial difficulty	1.889 (1.454-2.454)***	1.952 (1.404-2.713)***
[BRISQ31*32][CG21] Difficulty reconstructing meaning post-loss	1.269 (1.195-1.347)***	4.397 (2.579-7.947)***

	Univariate regression [BRISQ]	Univariate regression [CGRF]
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Intrapersonal predictors (n = 13)		
[CG25] Discovering the body		3.056 (1.998-4.673)***
[BRISQ09] Perceived difficulty in coping with loss	1.464 (1.088-1.971)*	
[BRISQ21] History of suicidal ideation	1.302 (1.019-1.664)*	
[BRISQ25] Feeling angry about the loss	2.212 (1.632-2.996)***	
[BRISQ26] Feeling empty or emotional numb post-loss	4.872 (3.051-7.729)***	
[BRISQ28] Feeling guilty about the loss	1.997 (1.530-2.607)***	
Interpersonal predictors (n = 10)		
[CG08] Lack of emotional closeness to the deceased		0.388 (0.210-0.715)**
[BRISQ13][CG09] High pre-death dependency to the deceased	1.547 (1.211-1.976)***	2.184 (1.557-3.063)***
[BRISQ12] [CG10] Problematic relationship with the deceased	1.020 (0.766-1.358)	1.046 (0.798-1.371)
[CG11] Unresolved regret to the deceased		1.051 (0.831-1.329)
[CG12] Caregiver burden		1.317 (1.039-1.670)*
[BRISQ04][CG13] Social isolation or low social support	2.114 (1.572-2.842)***	1.567 (1.227-2.001)***

	Univariate regression [BRISQ]	Univariate regression [CGRF]
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Interpersonal predictors (n = 10)		
[BRISQ05*BRISQ06*BRISQ07] [CG14] Insecure attachment style	1.017 (1.006-1.029)**	1.959 (1.446-2.617)***
[BRISQ18] [CG15] Poor family dynamics	1.210 (0.947-1.546)*	1.459 (1.148-1.853)**
[CG16] Low technology use		1.135 (0.811-1.558)
[CG17] Others are frequently concerned about how the bereaved is grieving		1.571 (1.185-2.083)**
Illness/death-related predictors (n = 6)		
[CG18] Suddenness of death		1.294 (1.025-1.635)*
[CG19] Perceived preventability of the death		1.399 (1.082-1.809)*
[BRISQ11] [CG20] Multiple concurrent losses / traumatic events	1.656 (1.233-2.225)**	2.607 (1.851-3.672)***
[CG22] Lengthy illness		0.803 (0.610-1.058)*
[BRISQ14][CG23] Perceived suffering while the deceased was dying	1.518 (1.134-2.031)**	1.457 (1.034-2.052)*
[BRISQ17][CG24] Perceived unpreparedness of the death	2.108 (1.420-3.129)***	2.635 (1.545-4.494)***
* p < .25, ** p < .01, *** p < .001 the first cut-off value of .25 is suggestive for exploring potential variables		

Table 5.14 Model 2 with background factors and bereavement risk factors (n=379 selected cases / 232 unselected cases)

Model 2 variables	Adjusted Odds Ratio (95% CI)
<b>Age</b>	
<= 30 years old	Ref*
31 – 45 years old	0.61 (0.011-0.336)**
46 – 60 years old	0.149 (0.026-0.873)*
>= 61 years old	0.011 (0.000-0.567)*
<b>Bereaved spouse (binominal)</b>	12.533 (2.787-56.360)**
<b>Frequent contact with the deceased before death</b>	0.515 (0.272-0.975)*
<b>History of mental illness pre-loss (ex. Depression or adjustment disorder)</b>	4.418 (1.708-11.428)**
<b>Multiple concurrent losses / traumatic events</b>	0.274 (0.122-0.613)**
<b>Perceived suffering while the deceased was dying</b>	0.138 (0.049-0.387)***
<b>Feeling angry about the loss</b>	3.183 (1.642-6.169)**
<b>Difficulty reconstructing meaning post-loss</b>	1.559 (1.274-1.908)***
<b>Feeling empty or emotional numb post-loss</b>	6.908 (2.264-21.071)**
<b>Discovering the body</b>	2.465 (1.296-4.687)**
* p < .05, ** p < .01, *** p < .001	

Table 5.15 The contingency table for cross-validating the predictive power of Model 2

Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	
60% selected samples	PGD	16 (TP)	5 (FP)	76.1%
	No PGD	5 (FN)	331 (TN)	99%
Overall % correct				87.55%

Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	
40% crossvalidating samples	PGD	4 (TP)	5 (FP)	44.4%
	No PGD	5 (FN)	209 (TN)	97.6%
Overall % correct				71%
***TN: True Negative, TP: True Positive, FN: False Negative, FP: False Positive				

### 5.3.4 Model 3 with background factors, bereavement risk factors and bereavement outcome factors

The third model was fitted by adding the third group of predictors, the bereavement-related outcome variables. The univariate logistic regression result suggested that the diagnosis of MDD, PTSD, resilience degree and meaning-making post-loss demonstrated significant predictability of the membership of the outcome variable. Among the four variables, MDD and PTSD demonstrated a correlation higher than 0.7 in the Pearson correlation test. To determine which variables to keep in the model fitting, we conducted several logistic regressions with different stepwise methods (forward and backwards) to determine which variable contributed to predicting the outcome variable. The PTSD variable was then selected for the multivariate logistic regression. The result of univariate logistic regression is presented in Table 5.16.

All of the significant predictors in Model 2 remained as significant predictors in model three (see Table 5.19 for comparison between three models and variables). The adjusted ORs in Model 3, despite adding PTSD variable, were also comparable to Model 2. The performance evaluation indicated that Model 3 had 64% true positive estimation of training samples and 40% of unselected samples (see Table 5.18). The AUC value of Model 3 was 0.831, indicating a slight drop in performance after adding PTSD variable.

The complete overview of three models is presented in Table 5.19. For the convenience of

comparing, the exact p-value is displayed in digits rather than indicated by the asterisks. Table 5.20 displays the ROC assessment of three models.

Table 5.16 Other bereavement outcome factors (n=379 selected cases / 232 unselected cases)

Bereavement outcome factors (n = 5)	Odds Ratio (95% CI)
MDD (CESD-R)	39.778 (4.098-386.064)**
PTSD (PCL-C)	42.108 (9.971-177.827)***
Resilience (CD-RISC-10)	0.942 (0.906-0.979)*
Integration of Stressful Life Experiences	0.768 (0.711-0.829)***
Posttraumatic Growth Experience	
Relating to others	0.920 (0.700-1.208)
New possibilities	0.856 (0.635-1.154)
Personal strength	0.772 (0.585-1.017)
Spiritual growth	0.865 (0.703-1.065)
Appreciation of life	0.841 (0.636-1.112)
Total score of PTGI	0.990 (0.975-1.005)
* p < .25, ** p < .01, *** p < .001	

Table 5.17 Model 3 with background factors, bereavement risk factors and bereavement outcome factors (n=379 selected cases / 232 unselected cases)

Factors	Odds Ratio (95% CI)
<b>Age</b>	
<= 30 years old	Ref*
31 – 45 years old	0.036 (0.004-0.304)**
46 – 60 years old	0.092 (0.012-0.704)*
>= 61 years old	0.004 (0.000-0.557)*
Bereaved spouse (binominal)	20.297 (3.193-129.001)**
Frequent contact with the deceased before death	0.306 (0.128-0.730)**

Factors	Odds Ratio (95% CI)
History of mental illness pre-loss (ex. Depression or adjustment disorder)	5.611 (1.891-16.646)**
Difficulty reconstructing meaning post-loss	1.649 (1.292-2.105)***
Discovering the body	2.863 (1.34-6.117)**
Feeling angry about the loss	3.361 (1.59-7.106)**
Feeling empty or emotional numb post-loss	12.188 (3.18-46.714)***
Multiple concurrent losses / traumatic events	0.188 (0.070-0.507)**
Perceived suffering while the deceased was dying	0.081 (0.022-0.291)***
Posttraumatic Stress Disorder	26.807 (2.776-258.871)**
* p < .05, ** p < .01, *** p < .001	

Table 5.18 The contingency table for cross-validating the predictive power of Model 3

Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	
60% selected samples	PGD	16 (TP)	9 (FP)	64%
	No PGD	4 (FN)	328 (TN)	98.8%
Overall % correct				81.4%

Sample size	Predicted condition	True condition of PGD		% Correct
		PGD	No PGD	

40% crossvalidating samples	PGD	4 (TP)	6 (FP)	40%
	No PGD	5 (FN)	206 (TN)	97.6%
Overall % correct				68.8%
***TN: True Negative, TP: True Positive, FN: False Negative, FP: False Positive				

Table 5.19 Three models with 60% samples for fitting model and 40% for cross-validating (n=379 selected cases / 232 unselected cases)

	Model 1		Model 2		Model 3	
	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value
Background factors						
Age						
<= 30 years old			Ref	0.011	Ref	0.019
31 – 45 years old			0.61 (0.011- 0.336)	0.001	0.036 (0.004- 0.304)	0.002
46 – 60 years old			0.149 (0.026- 0.873)	0.035	0.092 (0.012- 0.704)	0.022
>= 61 years old			0.011 (0.000- 0.567)	0.025	0.004 (0.000- 0.557)	0.029
Relationship to the deceased as a spouse	9.053 (2.976- 27.542)	<0.001	12.533 (2.787- 56.360)	0.001	20.297 (3.193- 129.001)	0.001
Relationship to the deceased as a grandchild	6.041 (1.960- 18.618)	0.002				
Being in a committed relationship	6.224 (2.401- 16.072)	<0.001				
Cause of the death due to fatal accident	3.172 (1.170- 8.603)	0.023				

	Model 1		Model 2		Model 3	
	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value
Background factors						
Frequency of religious activity	1.199 (1.01- 1.424)	0.038				
Frequency of contact with the deceased pre- loss			0.515 (0.272- 0.975)	0.042	0.306 (0.128- 0.730)	0.008
Bereavement risk factors						
History of mental illness pre-loss (ex. Depression or adjustment disorder)			4.418 (1.708- 11.428)	0.002	5.611 (1.891- 16.646)	0.002
Difficulty reconstructing meaning post- loss			1.559 (1.274- 1.908)	<0.001	1.649 (1.292- 2.105)	<0.001
Discovering the body			2.465 (1.296- 4.687)	0.006	2.863 (1.34- 6.117)	0.007
Feeling angry about the loss			3.183 (1.642- 6.169)	0.001	3.361 (1.59- 7.106)	0.002
Feeling empty or emotional numb post-loss			6.908 (2.264- 21.071)	0.001	12.188 (3.18- 46.714)	<0.001
Multiple concurrent losses / traumatic events			0.274 (0.122- 0.613)	0.002	0.188 (0.070- 0.507)	0.001



	Model 1		Model 2		Model 3	
	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value
Bereavement risk factors						
Perceived suffering while the deceased was dying			0.138 (0.049-0.387)	<0.001	0.081 (0.022-0.291)	<0.001
Bereavement outcome factors						
Posttraumatic Stress Disorder					26.807 (2.776-258.871)	0.004

Table 5.20 Comparing the Area Under the Curve (AUC) with ROC test

Model	AUC value (95% CI)
Model 1	0.574 (0.458-0.690)
Model 2	0.833 (0.731-0.935)***
Model 3	0.831 (0.729-0.933)***
*** significant at p < 0.001	

## 5.4 Discussion of the Quantitative Findings

Despite the relatively low percentage (4.9%) of PGD griever in our sample, data from our sample generates compelling results about PGD risk factors. With a proper weighting of the PGD griever's sample, the dataset allowed the extraction of equations to adequately explain the predicted probability of the binomial outcome variable (PGD confirmed) [254]. Overall, 15 out of 50 candidate variables exhibit potential predictive ability across three models. These variables are bereaved being younger than 30 years old, being a spouse of the deceased, being a grandchild of the deceased, cause of the death due to fatal accident, frequent religious activity, less frequent contact with the deceased pre-death, history of mental illness, difficulty reconstructing meaning post-loss, discovering the body, feeling angry about the loss, feeling empty or emotional numb post-loss, multiple concurrent losses/ traumatic events, perceived suffering while the deceased was dying, confirmed PTSD symptoms.

The advantage of this study is the transparent model fitting process that enables detailed comparison of different groups of predictors and evaluation of performance on each model. Conducting logistic regressions analyses often involves several attempts of fitting the models, adding/removing variables and observing the predictability of the model, which are the necessary steps to build the best model for describing the dataset. This technique has been used in other studies to evaluate the performance of the models and select the best models [262-265]. Since this study also possess an explorative nature to evaluate the candidate variables suspected and validated by field practitioners and researchers, the transparency of the model fitting processes can enhance the study reproducibility.

Below, a comparison of the three models, detailed predictor results, and the equation used to build the algorithm in Model 2 (which was selected for further implementation in the predictive algorithm in EtG) are presented.

### 5.4.1 The imperative need for a PGD risk factors measuring instrument.

Although a variety of validated bereavement-related measurements exist [37, 49, 238-241, 246, 266], our findings reinforce the imperative need for a scale specifically designed to measure PGD risk factors.

When we compared the performance of items on the BRISQ and the CGRF to risk factors measured by other grief-related questionnaires (e.g., ISLES-SF) and non-grief-related questionnaires (e.g., CESD-R), a decrease in predictability in Model 3 indicated that adding factors found on these measures did not contribute to the differentiation between normal griever and PGD griever. Furthermore, most of the 16 highly predictive factors in our models were measured by the BRISQ [236] and CGRF. Given that the bereaved often experience fatigue and difficulty concentrating, administering the least number of questionnaires capable of capturing PGD predictors can be more efficient. Thus, results from this study can be used to revise the BRISQ and CGRF by, for instance, omitting items that proved non-significant in predicting PGD in our sample.

### 5.4.2 Not many socio-demographic factors are effective predictors.

Using a three-model fit, we found that the bereavement risk factors most accurately predicted PGD (see Model 2, Table 5.14). Among all the 10 socio-demographic factors proposed (disregarding the six factors related to the deceased), four were significant predictors. The fact that many of the socio-demographic factors failed to predict PGD indicated that the development of PGD, although in coherence with literature [129], was influenced more by the presence of bereavement risk factors [128, 218], except if the griever was the spouse of the deceased [137]. Low levels of education was shown in previous studies to be a potential risk factor [267] but is not supported

by our study. Marital status showed significant correlation in the univariate logistic regression but the predictability was diluted when controlled with more variables. Age was only a significant predictor when other risk factors were present (Model 2 and Model 3). Our findings suggested that many of the socio-demographic factors (e.g., gender, educational level, employment status, marital status) did not increase a griever's risk of developing PGD.

### 5.4.3 Model 1 fitted with the background factors being the poorest performant model

The AUC value between 0.5 and 0.6 indicated that this model is a very poor model and is not applicable to yield any inferential to the dependent variable. The goodness-of-fit (Hosmer and Lemeshow) test of Model 1 is valid, but the ROC curve still suggests this unfortunate fact, meaning that the researcher should refrain from using Model 1 as a screening method since it fails to demonstrate relevant sensitivity and specificity.

Even though Model 1 will not be considered in building the screening app, it does exhibit some interesting insights for inferential statistics. One notable implication is the relative static characteristic of variables in Model 1, which are highly difficult to be moderated by psychotherapy. It suggests that these variables could be monitored both pre- and (immediately) post-death. Although our study yields some inconsistent findings in comparison to previous studies, such as gender [268-270] and (low) educational level [267], it is suggestive that these two variables are still included in the future studies. Except implementing the variables in screening model fitting, psychologists might find them helpful to identify sub-syndromal grievers, who may also benefit from professional guidance. Furthermore, the circumstances of loss are highly diversified, and researchers should note that different types of grief may not share the same risk factors. To stop exploring these potential predictive factors could instead discard opportunities to understand the possible conditions that turn these potential predictive factors into risk factors.

### 5.4.4 Model 2 fitted with background factors and bereavement risk factors being the most performant model

Adding the bereavement risk factors enhances the performance of Model 2 and could yield up to 76% true positive screening and the AUC value indicates that the model is good (0.833). Model 2 appears to be the most performant model. It includes 12 variables, nine of which are bereavement risk factors, showing that the bereavement risk factors exhibit much higher correlation to PGD. Out of the 29 proposed bereavement risk factors, 26 factors are potential covariates based on the univariate logistic regression, and only nine appear to be significant covariate in the multivariate logistic regression. The factors included in Model 2 and Model 3 are highly identical, with

Model 3 including one more factor, indicating potential saturation of the model. There are two insights based on this finding. First, in the circumstance of fitting a screening model, it is less meaningful to include as many variables as possible. Although many variables could be relevant for inferential statistics, and many psychologists would target on identifying as many related variables as possible, these variables do not necessarily contribute to calculating a performant model. The proof is the drop of performance in Model 3 after adding PTSD symptom. The second insight is that bereavement risk factors demonstrates strongest correlation to PGD, and at least nine of them (see the risk factors in Model 2) are possible to be applied across a variety of loss experiences.

The change in the background factors is also worth heeding. Being a grandchild, not being in a committed relationship, frequent religious activity, and death due to fatal accident are excluded in Model 2, and age and the frequent contact with the deceased pre-death are included. It suggests that the covariance of age and frequency of contact are significant with the presence of bereavement risk factors. The exclusion of other three factors is understandable. Since a great number of participants were the grandchild of the deceased, it could be due to the sampling bias that being a grandchild of the deceased is over-represented. Not being in a committed relationship implies that the bereaved is lack of support from partner, but does not suggest that he/she fails to seek support from other social figures. Previous literature also failed to reach a consensus regarding the cause of death as a predictor of PGD [234, 271, 272]. There is also not a clear categorization of types of cause of death. For instance, unnatural death does not necessarily correlate to traumatic death or violent death. Death due to fatal accident also does not suggest that the process of dying is traumatic. Therefore, the predictability of death due to fatal accident might be diluted when adding stronger predictors.

Two confirmed risk factors are identified in Model 2 (being a spouse of the deceased and discovering the body) [128]. Discovering the body is proven to be one of the strongest covariate of PGD, especially for female grievers who see the body at the suicide scene [237, 273]. Our study fails to support four out of six confirmed risk factors (for a review of the six confirmed risk factors, see Burke & Neimeyer, 2012, p.6). We further discuss this inconsistent finding in section 5.4.7. The next section discusses the evaluation of Model 3.

### 5.4.5 Model 3 fitted with most of the variables yet yields the opposite effect in performance

Model 3 includes almost all the same variables in Model 2 and further adds one more highly significant predictive variables (see the univariate analysis at Table 5.16), but the cross-validation result shows that the variation explained by Model 3 has decreased. The advantage of Model 3

is that it confirms most of the potential covariates, but with the cost that adding these variables confuses the classification algorithm.

Two insights are worth noting. The first is that bereavement outcome factors, disregarding their high relevancy to the PGD symptoms, demonstrate less effect in predicting PGD than the risk factors. The second insight has been discussed in section 5.4.1. Most of the existing measures of bereavement outcomes do not specifically target on risk factors measuring, and a measure related to bereavement risk factor is of imperative necessity.

The contribution of Model 3 is that it further intensifies our confidence that screening PGD with risk factors in Model 2 could be a valid approach.

#### 5.4.6 Comparison of the three models.

Judging from the performance evaluation, Model 2 demonstrates good performance in screening PGD despite having fewer predictors than Model 3, with Model 1 performing the poorest. Although background variables are included in all models, only four demonstrate significant correlation with PGD development. Thus, a greater number of variables did not enhance the ability to screen PGD, and may instead hamper the ability to discriminate a particular variable's contribution. Predictors that are significant in more than two models include: demographic factors (age, being the deceased's spouse), factors related to the deceased (frequency of contact with the deceased pre-death), intrapersonal risk factors (history of mental illness pre-loss, difficulty reconstructing meaning post-loss, bereavement risk factors, discovering the body, feeling angry about the loss, and feeling empty or emotional numb post-loss), illness/death-related factors (multiple concurrent losses / traumatic events, perceived suffering while the deceased was dying), and the two factors based on interaction of variables (importance of spirituality following violent/non-natural death, perceived financial difficulty while unemployed). Most of the factors that contributed to the prediction of PGD are intrapersonal risk factors.

#### 5.4.7 Inconsistent findings

Of particular interest, our results fail to substantiate some widely accepted, previously confirmed risk factors of PGD, such as low social support [55, 189, 190] and insecure attachment style [35, 274, 275], high pre-death dependency [35, 222] and high neuroticism [56, 225]. The only difference between the confirmed and potential predictors is that the confirmed risk factors are supported and empirically proven to be PGD risk factors, and they should be strongest among other proposed risk factors. The fastest and most unlikely conclusion to draw from our finding is that these confirmed risk factors may not be a covariate of PGD, but then we also risk ignoring the hidden opportunities to reconsider the reasons lying behind the inconsistency of findings. Therefore, below we discuss the potential cause of this inconclusive finding.

Low social support has been shown to be a significant risk factor in numerous studies [55, 136, 147, 149, 150, 189, 190, 276-278] but was an insignificant predictor in our study. A straightforward explanation is that confounding variables are not measured and because of this, a relationship between the proposed risk factors and the outcome variable are not detectable. For instance, social support can be measured using single items or with validated questionnaires. In this study, we measure social support by asking if the griever wished for more support from family or friends (BRISQ) and if the griever had other important figures to share their feelings with (CGRF). Using single items as our study might have limited our ability to capture various dimensions of social support, which potentially served as a confounding variable. Another interpretation of the result is that social support might only predict PGD if the griever felt it was needed or if they were dissatisfied with the support received [188]. Another proof is the exclusion of the variable, in a committed relationship. Being in a committed relationship does suggest that the bereaved can seek support from their partners, but it is only a small part of the big social support picture. This variable is a significant covariate in Model 1 but is excluded after more risk factors are present, showing that it demonstrates potential to predict PGD but confounds with other more correlated covariates. Therefore, in measuring social support and other psycho/socio/spiritual phenomena that tend to be complex, the use of measures specifically designed to capture nuanced aspects of these issues [279, 280] versus individual items might be warranted.

Similar to social support, attachment style is a multi-dimensional psychological concept that likely is best measured using a specified measure to avoid the occurrence of confounding variables [281, 282]. In this case, insecure attachment style is used as an overarching variable that represented pathological attachment styles, in general. To accurately judge the relation between attachment style and the development of PGD specific types of insecure attachment style, such as avoidant and ambivalent, should be assessed.

On the contrary to the previous two variables, high pre-death dependency is proven a strong risk factor when the bereaved is the spouse of the deceased, and the bereaved relies strongly on the deceased pre-death [35, 222]. This variable has a different layer of implication. The original variable in the review paper is pre-death "marital" dependency to the deceased, suggesting a marital relationship between the griever and the deceased. In our study, we rephrase the variable to examine whether it remains a significant covariate for non-spousal bereaved and the result fails to support its relevancy. Furthermore, being a spouse is a significantly strong predictor across all three models, which makes separating the dependency issue and the spousal risk difficult and the applicable conditions narrowed. It is better to examine pre-death dependency with non-spousal bereaved, and more evidence would enable

us to conclude the possibility of it confounding with being a spouse of the deceased.

The last insignificant confirmed risk factor is high neuroticism. It is interesting because high neuroticism was considered potential predictor of Depression [283-285] and PTSD [286, 287], two mental disorders that were highly correlated to PGD. Furthermore, instead of high neuroticism, history of mental illness pre-loss is a significant predictor in Model 2 and 3. This finding suggested that high neuroticism might exhibit higher correlation to the “risk factor” of PGD. In other words, high neuroticism can be the covariate of history of mental-illness rather than to PGD. It explains why high neuroticism is a significant predictor in the univariate logistic regression ( $p < .001$ ) but is excluded in the presence of history of mental illness. To validate this finding, more studies are needed to clarify the relationship between high neuroticism and other risk factors.

#### 5.4.8 Variables that have adjusted ORs under lower than 1

Interestingly, some of the proposed factors show ORs lower than 1, implying that one unit increase in each of these factors indicates the odds decrease for the exposed individual. Hence, these factors might suggest a negative association to PGD. According to Model 2, potential protective factors included: frequent contact with deceased pre-death (adjusted OR 0.515), multiple concurrent loss/traumatic events (adjusted OR 0.274), perceived suffering while the deceased was dying (adjusted OR 0.138). Judging from the interview result in Chapter 3, the griever wish to spend more time with the dying loved one. Hence, the more frequent contact with deceased pre-death, the less the griever might experience complication of grief. In particular, multiple concurrent loss/traumatic events and perceived suffering while the deceased was dying are proposed in the risk factors questionnaires, but exhibit negative correlation with the dependent variable in the multivariate models. This unexpected result argues for a reconsideration of the items used to measure them. Our previous reasoning was that the more concurrent loss/traumatic events the bereaved experienced in addition to the loss, the higher possibility that the bereaved was overwhelmed and prone to develop PGD. Similar to this reasoning, the more the bereaved perceived the deceased was suffering while dying, the higher susceptibility to developing PGD. Our model indicates a completely opposite tendency. Below are possible explanations.

The first explanation is that we have ignored the reasoning in reality. For instance, if a mourner perceived that the loved one suffered while dying, death might be viewed as bringing final peace and end of suffering to the loved one. However, due to the limitation of study design, the average time we collected the data is 25.22 months post loss. If given this amount of time, mourners may reappraise their perception of the dying process, say, from empathizing with the pain of the deceased to convincing themselves that the deceased is no longer suffering.

According to the diagnostic criteria of PGD, if griever develops PGD, they should experience difficulty to reconstruct meaning for a long period. Due to the cross-sectional design of our study, we cannot conclude immediately that perceived suffering is a risk factor or protective factor. It is better to evaluate this factor at two time points (within six months and after six months) to help us draw a more confident conclusion.

The second explanation is due to the scale of the questions. As section 4.6.3 suggests, the wording of the question can cause confusion on the scope of the variable. Experiencing multiple traumatic events “simultaneously” with the death of loved one can be quite different than experiencing these events “before” the death of loved one. The possible reasoning is that experiencing multiple challenging events altogether will overwhelm the griever, but not when the events are happening following or before the death of loved one. If the events occurred before the loss, mourners are expected to be more resilient towards life challenges. The language used to measure this variable does not suggest these events happening at the same time.

A more statistical explanation is these variables are protective factors when other risk factors are present. In section 5.4.7, pre-death dependency does not demonstrate significant association with the dependent variable because the marital condition is not present. The evidence is that these two variables do yield significantly positive association in the univariate logistic regression, but show negative association when other risk factors are added. With the presence of other risk factors, griever who manage to (1) frequently contact the deceased pre-death, (2) survive other traumatic events before losing a loved one, and (3) believe that the deceased are no longer suffering might indeed adapt to the fact better.

However, these explanations are not applicable to age. Although age demonstrates adjusted ORs lower than one, since all of the age groups exhibit potential correlation to PGD, we have to consider their relative relationship. The rest of age groups except the reference group (age under 30 years old) all exhibit adjusted ORs lower than one, suggesting that the odds will decrease when exposed to these variable groups. This makes the reference group at relative risk (the odds remains unchanged with exposure), meaning that age under and including 30 years old could be a risk factor. It also adheres to the reviews that younger age of the bereaved can be at risk of developing PGD [128].

#### 5.4.9 Limitations on the analysis method

Our preference was that all 50 variables, after removing the highly correlated ones, would fit into one model. Additionally, as estimated by a power analysis, 300 participants was deemed ample to yield sufficient analytical results. In our case, however, through MTurk we collected twice that



number of respondents. Furthermore, SPSS was unable to adequately analyze the large amount of data stemming from the high number of variables/participants because of the large number of categorical variables. For calculating OR, at least four groups of cases must exist: exposure to a variable with outcome, exposure to a variable with no outcome, no exposure to a variable with outcome, and no exposure to a variable with no outcome. If one of the groups is missing, the calculation will fail. Our MTurk sample could not satisfy all of the possible combinations of the categorical variables. With more variables, especially categorical variables, included in the analysis, it required a much larger sample size (rule of thumb may yield an ideal sample size of 900, but it is suggestive to add more samples by carefully review the options in the categorical variables) to fulfill all the possible combinations of groups. Therefore, we opted to analyze the factors by groups.

Additionally, in cross-validating the three models, due to the variation of the numbers of valid cases in each group of variables, the number of included cases varied slightly. For instance, there were only 24 PGD grievors included in the first model due to the participants indicated missing value and 29 included in the second and third model, resulting a higher chance to yield a radically large or small percent of correct due to having less samples (e.g., 2 out of 4 correct makes it 50% correct). However, the algorithm of SPSS will fail if the samples collected are not capable of covering all the potential combination of variables (see 19.4.2 *Incomplete information from the predictors* from the book of Field, 2013) . The model calculation process did not throw an error and this suggests that the sample successfully fulfill the goodness-of-fit assumption. Therefore, the influence of sample number variation on the validity of the model could be considered minimum.

## 5.5 Qualitative Findings

In the completion page of the app, we also designed a section in which we invited comments or feedback from participants. It was optional channel to express the feeling of participating in the study and also assisted us to gauge to what extent participants were interested in the study. Out of 620 participants who visited the completion page, 271 provided extra comments, which means almost 43% of the participants spontaneously offered opinions. It was surprisingly encouraging for us, and allowed us to understand participants' experiences of using the app. The qualitative findings were more insightful for the HCI field, and in this section, we will focus on discussing the qualitative findings that were related to user experiences.

### 5.5.1 Positive messages

Perhaps due to the financial compensation, we received superabundant *thank you* messages. Fortunately, lots of the comments were quality comments and provided great nuances about the participants' experiences on the navigation and feedback. This section presents some of the positive comments provided by the study participants.

*Feeling emotionally challenged in the process.* Participants indicated that taking the survey reminded them the positive and negative memories about the loved ones. Some of the participants specifically mentioned that they cried through parts of the study. This finding is highly aligned with our design purpose, to stimulate the bereaved to revisit and reappraise their grief. Despite the fact that the process was emotionally stressful, participants also thought that the questions were thought provoking and helpful in pointing out the perspectives that they never thought of. It has proven that well designed questions play an important role in thought changing and could potentially lead to reassessing of the behaviors or coping style. Some of the comments are listed below (the Uid numbers are corresponding to the ids the participants were assigned in the MySQL database):

*"It was a very interesting experience. I cried through part of it. my mom was my best friend and two years after her death it is still hard to deal with the loss. I think that completing this survey and the feedback it gave me did make me feel a little better about how I am handling it."* – Uid676 (60 years old female, lost mother)

*"Very interesting study and this could be a helpful application. It helped me look at areas of my friends death that I hadn't looked at before, some I hadn't even connected that it could be because of her death."* – Uid215 (55 years old male, lost friend)

*"It was a little helpful for me, but also made me reflect on some negative emotions I did not really want to consider. Overall, I felt it was probably worthwhile for me."* – Uid122 (27 years old male, lost great grandmother)

*"This was a really nice experience. I sort of relived going through my grandmother's death, yet I also got to experience a lot of nice memories from when she was alive. I thank you for allowing me to take part in this experience!"* – Uid337 (19 years old male, lost grandmother)

*The app worked smoothly and the interface was user-friendly.* It seemed that the modifications on the navigation features and interface were basically successful, since a lot of participants have reported enjoying the smoothness of the interface. Participants also generally enjoy the navigation feature of highlighting the next section and breaking down questionnaires into different groups. *Feeling reassuring and informative through reading the feedback.* The feedback was frequently



regarded as insightful, interesting, educational, thoughtful or eye opening. Furthermore, although it was not the focus of the study, one participant did reflect on the comments and realized that he/she might need help.

*“This was very interesting and informative in regards to how poorly I am doing after my father’s passing. Unfortunately, I have realized most of this but have failed to seek treatment. I wish there would have been a section just to explain what happened to me.” – Uid528 (39 years old female, lost father)*

*“I think it help me learn somethings and maybe I do need to get help now.” – Uid340 (38 years old female, lost mother)*

Many participants also felt that they have learned something about themselves and believed it was a comforting and therapeutic process. One participant mentioned that the scientific confirmation about her grief situation was especially helpful for his/her healing process.

*“this is a wonderful thing. even though I feel strong and feel my healing and acceptance taking place...this study questionnaire is an amazing thing and should be shared with many people. it made me feel a sense of confirmation not through spiritual eyes only, but even through science, it is like science and faith crossed and confirmed that each are useful and real and both can help continue the healing and the understanding for humans as we are with this life in this world that we have been momentarily given.” – Uid527 (43 years old female, lost son)*

*“I think GIFT is very interesting. I appreciated all the post-survey feedback and I felt it was accurate and helpful. Although I still grief everyday, I did not think or worry that I had depression or PTSD so seeing the feedback validated my thoughts. The feedback also offered helpful advice which I will seriously consider.” – Uid125 (46 years old male, lost partner)*

### 5.5.2 Complains and negative comments

*Lengthy study.* The study generally took 23 to 25 minutes to complete. According to the modern standard, it might be too lengthy especially for a sensitive and emotionally triggering survey like GIFT. Although the researcher expected that the feedback would relieve the stress of doing the study, a few participants still pointed out that they thought the study took too long to complete. *Feedback was at the surface level.* One participant was annoyed by the feedback and thought the questionnaire did not apply to her. It might be a single case, but it should be included for future reference.

*“I don’t understand what the point of this is. What’s the gift? A better understanding of myself? I don’t know that I actually got any take away points from the assessment*

*scores. Having a sense of okay, I guess i’m not depressed enough for this program to be worried about me is nice, but what am I to make of it beyond that? Also, as someone who has done lots of personality assessments, these seem pretty surface level. It’s hard for me to take the assessment score in a meaningful way when there are only 10 questions and half of them don’t apply because I’m not religious.” – Uid89 (37 years old female, lost father)*

*Compensation not worth the time and the emotional turmoil.* From the perspective of IRB, higher payment was not encouraged and should not be the main motivation that the participants were participating. The ideal circumstance was that participants were interested in the subject and felt spontaneously motivated to join, which was quite rare in practice. A few participants mentioned that the payment was too low for such as long study and for experiencing this degree of emotion triggering.

*“Just that it was very long and emotional for the pay.” – Uid597 (36 years old male, lost friend)*

*“Your pay is garbage. How can anyone support themselves with 2 or 3 dollars an hour of pay? It is shameful.” – Uid557 (35 years old male, lost son)*

Although the compensation was not satisfactory from the participants’ point of view, it did not necessarily hamper the quality of the data gathered from the study. Our concern was that higher compensation might also cause participants to lie to participate in this study. It was a dilemma that we might have to seek to balance in the future.

*Collecting too many redundant information.* One participant indicated that although he/she liked the app, there were information that he/she thought unnecessary to give, such as gender, age or race. The information collected were necessary for the exploratory analysis of risk factors, but the final deliverable would omit unnecessary questions (and questionnaires). In addition to that, Amazon also strictly forbids the collection of email address, username or password, which caused us to modify the login system in the middle of the study. It was a valuable experience learned from the study.

### 5.5.3 Potential future development- Story sharing and networking

Although we did not expect to receive participants’ grief stories, many of the participants shared their stories spontaneously in the feedback messages. Some of them shared really private details about their loss experiences and wrote really quality comments. It seemed relatively unusual to give private stories to unknown strangers, especially when the participants were basically interacting with the app (website). However, we did receive the quality sharing such as personal as the following two:

*“Answering these questions was somehow very comforting, as was seeing the results you provide. I am two days away from the 2nd anniversary of my sister’s death, and am very tender about her loss right now, the timing is special to me. I am still feeling her loss every day. I lost both my brothers and my sister in a very short span of years, I am the Last of the Mohicans and that is not a happy thing. I’ve also had other significant losses in the same time frame, my closest friends are suddenly also passed away. I have been feeling like I know more people in Heaven than I do here, now. This study took me through the many stages and reactions I lived through, the questions were sensitive and on target. Thank you. I just need to thank you for the comfort this has given.” – Uid243 (67 years old female, lost sister)*

*“My friend was murdered by 2 people he sold drugs to. They tried to rob him of his drugs and his money and when he wouldn’t give it up they shot him, stole his things anyway and ran. This happened out of the blue and took me for a loop, I never imagined this would have happened at all - despite what is in the news about him in my hometown he was one of the nicest people I had ever met. I was a little wary about taking this survey but pouring my emotions and thoughts into a survey with questions as if it KNEW me helped a little. I feel better than I did before I took this survey. I don’t have any legit feedback on how this application worked, but if someone is reading this then thank you for somehow finding me when I needed it.” – Uid380 (21 years old female, lost friend)*

It was an interesting phenomenon for us, since it was a discovery that we did not expect. It also implies the potential combination of EtG and My Grief Journal, an unused prototype developed at the second stage of the previous study (see Chapter 4). There was a need for participants to share their stories, and it seemed to be made easier by an online communication. Combining this insight with the comments of the participants from the protocol analysis study (see the discussion in Chapter 4), we could conclude that grieving users have a need to share stories and also read other griever’s stories. Perhaps they also wish their stories to be read. In addition to sharing the stories. One participant also suggested to have a chance to hear other people’s stories and support others.

*“Great to give some direction with where we go in our grief process. I would like to hear some stories from others so that maybe we can network and support each other in our grief.” – Uid135 (38 years old female, lost brother)*

The deployment of GIFT has proven good potential of empowering the bereaved, but we also observed users requesting for more functions such as reading others’ stories or sharing their results. It shows that users would need more functions to fulfill their various needs in bereavement,

which will require a large-scale portal to attend these needs. Developing GIFT is one of the steps in building the screening algorithm for EtG, and designing a holistic bereavement service portal is not included in the scale of this research. However, the qualitative insights can contribute to the future development of a more holistic self-monitoring system for bereavement and give EtG a more guaranteed starting point for UX design.

The quantitative findings would be implemented on EtG as the predictive algorithm. What we learned from the participants’ feedback is that the participants were still nudged to revisit, reassess and reconsider their behaviors, thoughts and circumstances during the bereavement. Interacting with a PSS like GIFT would inevitably yield effect on the griever’s thoughts or behaviors and we could expect that so would interacting with EtG yield the similar effect. The feedback from the participants showed more positive effects than negative, and more therapeutic effects than agonizing, suggesting that providing meaningful feedback regarding the griever’s bereavement circumstances, when implemented in a non-clinical context and on EtG, still has a potential to yield a positive influence to the bereaved.

## 5.6 General Discussion

### 5.6.1 Reflection on sampling through Mturk

A big lesson learned from testing an application on Mturk is that researcher should never require participants to register or gather participants’ email address on Mturk. We had to modify the login system to utilize participants’ Mturk ID instead of email address, or else Amazon would remove the task. It was a big problem for this study because of the way GIFT was designed. Future researchers should always avoid violation of Amazon’s policy before designing a data collection system.

Some studies have supported the quality of data gathered from Mturk and concluded that it is a cost-effective approach to gathering a good variety of samples from the general population [250, 251, 288]. However, the findings in this study posit a different concern for studies which aim to evaluate severe grieving samples. Our primary intention is not to assess the quality of sample gathered from Mturk, but since all of our study participants are recruited from Mturk, and the prevalence of PGD griever is almost half of the suggestive prevalence from the meta-analysis, this fact should concern future researchers. One of the biggest worries was that users from Mturk could twist their answers to participate in this study. In this study, the system record showed that two users intentionally modified the relationship between the deceased and the time the deceased died to participate in this study. Fortunately, this proportion was very

low. The second problem is that around one out of ten participants tend to click through the questionnaires. For the participants who complete the questionnaire in an unusually short time (e.g., spending less than one minute on the background information questionnaire), we need to check the answer carefully. In our case, only a few of them are obviously questionable answers. Most of the data are still reasonably good. These concerns do not necessarily endorse Mturk immediately as a good source for gathering griever's opinions but support its vast potential to collect quality data with proper system design and safeguard from researchers. If more bereavement-related studies are to be conducted on Mturk, the sample from this study would be a nice reference for considering Mturk as a recruitment approach.

### 5.6.2 A critical path towards the development of a preventive intervention for PGD

Not surprisingly, the ultimate goal of predicting PGD in the early phase of bereavement is to develop effective preventive interventions. Although previous studies indicated that the effect of preventive interventions on PGD remains invalidated, one of the possible reasons could be the lack of instruments to screen potential prolonged grievers at the first six months [9]. Establishing a valid method for screening PGD can be a critical path towards preventing it. Furthermore, as suggested by the results of this study, there could be more than one approaches to predict PGD. In the process of developing a predictive model, the researcher also identified other non-clinical needs such as the need to assist griever's decision making, or the need to build effective communication between family members. These needs might not be of interest to psychotherapeutic fields but can be insightful for further design of supporting technologies.

### 5.6.3 Conducting factor analysis (principal component analysis) to further reduce the dimension of predictive factors

Although we examined the correlation and multicollinearity before including the variables in the model and combined or removed the highly correlated variables, it is more suggestive to conduct a factor analysis or principal component analysis to extract the critical components measured by the questionnaires. More efforts are needed to enhance our understandings of the effective predictive factors, but the data gathered from this study would also serve as a great base for the exploratory data analysis of BRISQ and CGRF.

## 5.7 Implementing the Screening Method in EtG

GIFT marks a step forward to building the screening algorithm for PGD, which constructs the major contribution of the thesis, an internet-based self-screening app for screening PGD

in the early phase of bereavement. To develop a screening method that targets lay users, psychological outcomes, and professional jargons need to be translated into a more appealing and understandable form. For researchers that aim to evaluate the predictive variables, adjusted ORs and the p-value (sometimes the 95% CI) are frequently reported [261, 265, 267, 289]. These findings are reported in section 5.3 and discussed in section 5.4. It is meaningful viewing from inferential statistics' point of view but can be hard for nonresearchers to interpret. For instance, an OR of 74 on the spouse variable means that the OR of a griever developing PGD is 74 times as large as for spousal griever than for non-spousal griever. OR could not directly refer to the predicted probability, and is frequently misinterpreted by the researchers [261]. Instead, when we calculate the probability of developing PGD from a spousal griever and a grieving daughter with Model 2, provided that the exposure to other risk factors remain unchanged (e.g., violent death, unemployed and feeling financial pressure, emotional numb, etc.), the probability of spousal griever to develop PGD is 36% and grieving daughter 1% (the equation is described below). In our opinion, this result will be much more interpretable and reader/user-friendly.

The advantage of EtG is that it simplifies the complicated calculation process and present the result in a more interpretable manner for lay readers. This section concentrates on how to translate the psychological results into a usable internet-based PSS.

### 5.7.1 The formula for implementation in EtG

Model 2 is selected for further implementation in the EtG algorithm because of its thorough inclusion of risk factors and best performance in the cross-validation and ROC curve assessment. The extracted formula from Model 2 to calculate the predicted probability  $\rho$  of PGD existing is as below.

The program first calculates the logarithm of the odds of the predicted probability  $y^*$  and utilize the  $y^*$  to calculate the predicted probability of the outcome variable happening. It resulted in the following equation for calculating  $y^*$ . The  $\beta$  (coefficient) value of each covariate is the inverse of its adjusted OR and is displayed in Table 5.21 for reference.

$$y^* = \text{bereaved\_spouses} * 2.528 + \text{age\_between\_31\_to\_45} * (-2.804) + \text{age\_between\_46\_to\_60} * (-1.902) + \text{age\_above\_61} * (-4.522) + \text{frequency\_of\_contact\_with\_deceased} * (-0.663) + \text{mental\_illness\_history} * 1.486 + \text{multiple\_concurrent\_losses} * (-1.295) + \text{perceived\_suffering\_while\_deceased\_was\_dying} * (-1.978) + \text{feeling\_angry} * 1.158 + \text{feeling\_emotional\_numb} * 1.933 + \text{difficulty\_reconstructing\_meaning} * 0.444 + \text{discovering\_the\_body} * 0.902 + (-13.901).$$

Then the variable  $y^*$  was implemented to calculate the estimated probability  $\rho$  of PGD happening with the following equation (for the explanation of this equation, see equation

4 of Peng *et al.*, 2002, p.5) . In the equation, we first exponentiate  $y^*$  with the SPSS default calculating function  $\exp(y^*)$ . The rest of calculation can easily be done.

$$\rho = \frac{\exp(y^*)}{\exp(y^*) + 1}$$

If the estimated probability  $\rho$  of PGD happening is larger than 0.50, the system would determine that the griever is at a higher risk of developing PGD. A table for example cases is presented in Table 5.21.

Table 5.21 Predicted probability of 4 cases

Case No.	26	540	2	531	83
Bereaved spouse $\beta = 2.528$	No	Yes	No	Yes	No
Age between 30 to 45 $\beta = -2.804$	No	No	No	Yes	No
Age between 46 to 60 $\beta = -1.902$	No	Yes	Yes	No	Yes
Age above 61 $\beta = -4.522$	No	No	No	No	No
Frequency of contact with deceased pre-death $\beta = -0.663$	2-7 times per week	Everyday	2-7 times per week	2-7 times per week	Everyday
History of mental illness $\beta = 1.486$	Quite a bit	Somewhat	Somewhat	Quite a bit	Quite a bit
Multiple concurrent losses/traumatic events $\beta = -1.295$	Somewhat	Quite a bit	A little	Quite a bit	Quite a bit
Perceived suffering while deceased was dying $\beta = -1.978$	Not at all	Very	Slightly	Very	Extremely

Case No.	26	540	2	531	83
Feeling angry about the loss $\beta = 1.158$	Slightly	Extremely	Somewhat	Very	Very
Feeling empty of emotional numb $\beta = 1.933$	Rarely	A great deal	Occasionally	A moderate amount	A great deal
Difficulty reconstructing meaning post-loss $\beta = 0.444$	Quite a bit * Very much	Very much *	Slightly * Slightly	Quite a bit *	Very much *
Discovering the body $\beta = 0.902$	Strongly disagree	Strongly agree	Agree	Agree	Strongly agree
Intercept $\beta_0 = -13.901$	-	-	-	-	-
Predicted probability	0.24	1.00	0.00	0.17	0.84
Predicted result 1 = PGD griever 0 = Non PGD griever	0	1	0	0	1
Actual result 1 = PGD griever 0 = Non PGD griever	1	1	0	0	1

### 5.7.2 Designing the research deliverable, Empowered to Grieve (EtG)

Following the implementation of the predictive algorithm and analyzing the participants' experiences, the insights gathered from deploying GIFT have provided useful design implications for EtG. These implications are listed below. The deliverable is shown in Figure 5.15 to 5.18.

*Reduce the questionnaires required for the prediction.* The inclusion of nine questionnaires has resulted in some complains, suggesting that a lengthy session is highly undesirable. It is suggestive to select the questions more targeting on the critical variables for calculating the



predicted probability. EtG should remove the socio-demographic questionnaires but only keep the key questions such as the relationship with the deceased loved one. The questions could be integrated into the risk factor questionnaire.

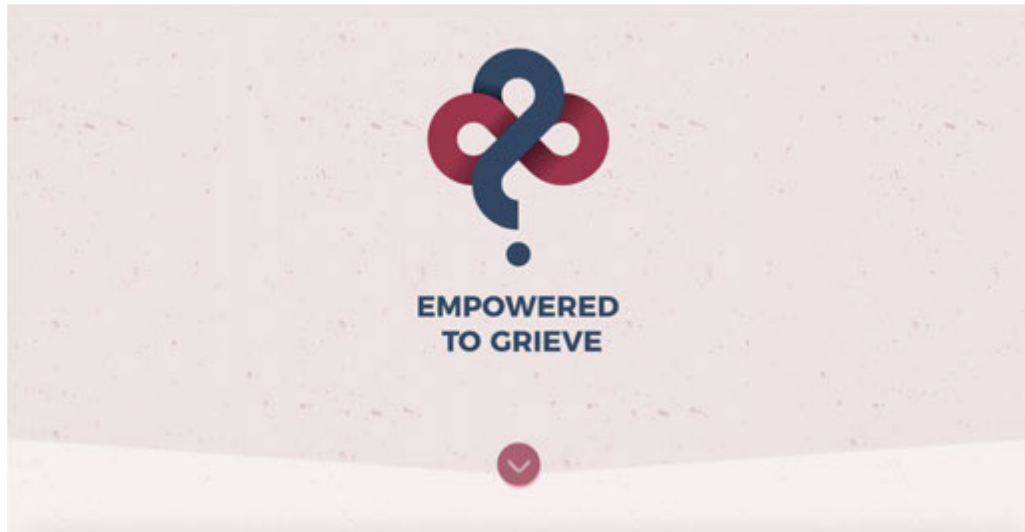


Figure 5.15 Welcoming page of EtG

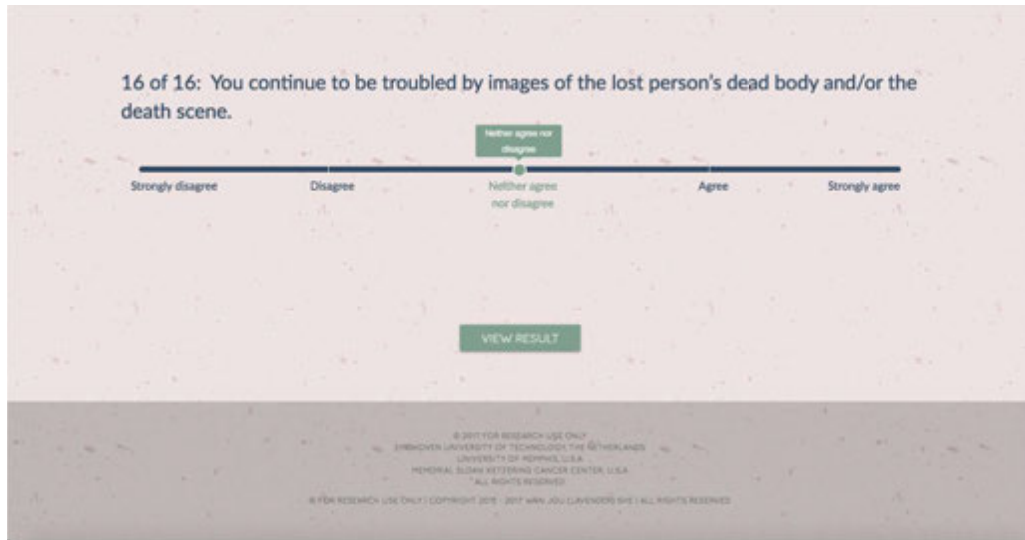


Figure 5.16 Total 16 questions of the questionnaire



Figure 5.17 The feedback displayed with visual result



Figure 5.18 Downloadable figure with feedback

However, since some participants also welcome more questionnaires that helped them to understand different perspectives of bereavement, other questionnaires, which if are publicly accessible and can be allowed to administer through EtG for a larger population, and feedback can be made optionally available for users who might be interested.

*Generate a report that can “take away.”* EtG does not require the users to create a profile since it is not designed primarily for data gathering and analyzing. If the users do not keep the report in their profiles, the report should be in the format that they can download, send or print. The



basic take away points should include the predicted susceptibility to PGD, potential feedback and suggestions for the users, and the useful information or links to supportive resources. EtG is currently administered as a web application. Although it can be accessed through every kind of (personal and mobile) devices provided a browser is installed, there should be an easy way to save and share the report. The format that can best contain all the feedback is a pdf report, but it is unappealing if users wish to share the result on a social network or another platform. Therefore, EtG should offer an infographic with the visualized scale and other essential information in a jpeg format. There should be a one-click button to export or share the report on different social networks or platforms.

### 5.7.3 The practical consideration of implementing EtG in the real world

EtG is currently a single function app that serves to screen PGD in the first six months of bereavement and provides a user-friendly translation of psychological measurements and feedback to the bereaved lay users. It is a step toward empowering the bereaved in the very early (perhaps even beginning) phase of bereavement. However, according to the participants' feedback of using GIFT, the bereaved could benefit from a more versatile website that offers various functions that attend their needs, and, as they move forward in the coping process, enables their coping activities (see the meaningful activities discussed in Chapter 3 for more examples). It can also be expected that EtG could include more functions in the future following the primary feedback the bereaved receive and provide more personalized coping suggestions that could mediate the necessary coping activities. A more straightforward way is to embed EtG in a more holistic and mature bereavement support portal as part of the service. It is true that we as researchers often develop applications with genuine kindness, but we should be cautious to presume that users will spontaneously intend to use EtG and trust the feedback. Another possible approach is to introduce EtG into a clinical or psychotherapeutic environment since it is a potential channel to approach individuals who might need it. In this way, we could make EtG valuable not only in the research context but also in a practical context.

## 5.8 Limitations and Future Research Opportunities

In this study, we examined 50 potential predictive factors for PGD with GIFT, an Internet-based data gathering instrument designed to gather participants' bereavement experiences and feedback on UX of the self-monitoring app. The major contribution of this study was the many variables included and evaluated. Many previous studies [51, 128, 129, 170, 189, 190, 217-221, 265, 267, 289, 291-295] have attempted to predict PGD with several risk factors but none of which had included as many factors as our study. The findings also clearly indicated that by

adding more variables, the predictive power of the model could both increase or decrease, and some variables that were significant could confound with other variables and were excluded in the equation. Therefore, this study is of great advantage in identifying the most significant variables while taking into consideration of most of the currently identifiable candidate variables.

Out of the 50 candidate variables, 15 variables are included in the final model, suggesting that less than half of the proposed variables demonstrate significant associations with PGD. Among the 15 variables, 11 variables are proposed as PGD risk factors and almost all of the PGD risk factors validated by the models are in line with the previous literature (see the review of Burke and Neimeyer, 2012) except three variables, frequency of contact with the deceased pre-death, multiple concurrent losses/traumatic events (included as a Loss-oriented stressor in Stoebe et al., 2006, p.2444) and perceived suffering while the deceased was dying (included as one of the risk factors in Lobb et al.'s (2010) review). These three variables appear to demonstrate a negative association with PGD, which is different to the fact that they were proposed as potential stressors and risk factors in previous literature [129, 218, 274]. More studies would be needed to examine this inconsistent finding.

Our study fails to support the significant correlation between PGD and the other 35 variables, and several explanations can be given. The first explanation is that these variables confound with the 15 significant variables, resulting in possible spurious finding in previous studies. The second explanation points to the difference of measuring instruments. Three of the questionnaires used in our study are in development and are possibly different to the measurements administered by other researchers (for the discussion, see section 5.4.7). The third explanation has to do with the cross-sectional design of the data collecting strategy. Although our candidate risk factors are either factors that are highly static or hard to be moderated by psychotherapy, the time we collect our data is in average 24 months post-loss. It limits us from drawing a firm conclusion based on the level of the variables at time zero (or in the past). Therefore, a longitudinal study or a study that measures at least two time points are highly recommended to be a follow up for this study. Even though, the contribution of this study is to unfold and explore as many variables that possessed potential to predict PGD based on reviewing previous studies [128, 218] and the field experiences. It has to be emphasized that bereavement, or PGD, is a multidimensional experience, and conducting specific studies that target on a certain type of loss experiences would help to facilitate a more precise and nuanced evaluation of various types of risk factors.

The generalizability of our study should also be clarified for a clear interpretation of this study result. First, this project is carried out in the Netherlands and the United States (after the pilot study, we specified to recruit participants within the United States on Mturk), and

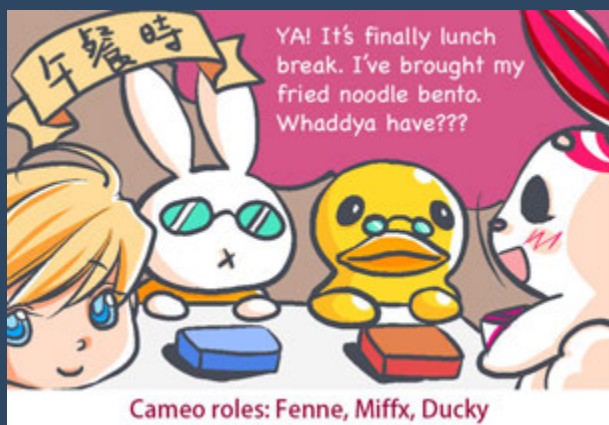
most of the participants are native English speakers, or at least proficient in English. Therefore, the study result may not be completely applicable for the bereaved from the different cultural background such as the Asian bereaved. Second, most of the findings derived from our study are based on the cross-sectional data collected after six months of bereavement. Although studied factors are believed to demonstrate static interactions with the outcome factor and also supported by other literature [128, 218, 236, 295], our findings still can face a certain degree of limitation in generalizing the findings to the group bereaved less than six months. In some situations, the level of these factors could fluctuate. For instance, the participants might be in the middle of psychotherapy, resulting in a lower level of difficulty in meaning reconstruction. Such case could reduce the rate of individuals sampling positive of PGD symptoms and cause false negative classification and underestimation of the risk factors in the screening method. However, we tried to cope with this bias by utilizing the statistic method to correct the data, reducing the risk of underestimating the level of risk factors. Our screening method is also has limited application to delayed grief because it assumes the grief level either stay the same or drop at the beginning of loss [296].

Another limitation of this study is that the applicability of the predictive model with the individuals who have experienced multiple losses still needs further evaluation. In the current model, the calculation was based on the risk factors associated with a single death event. It is hard to conclude that the impact of risk factors would remain the same even though griever experience multiple deaths of loved ones. More investigations on the applicability of the predictive model should be conducted for individuals who suffer from multiple deaths of loved ones.

This study implements an unconventional setting to gather the insights that answer the research question. On the one hand, we aim to build an empirically-validated regression model for providing more meaningful feedback to the bereaved (lay users). On the other hand, we need more insights on the user experience perspective to assess the benefit/challenge of providing feedback to the bereaved. It is hard to achieve both in one study, and the primary focus was developing the screening method. To deepen our knowledge of the experiences and attend to users' needs in monitoring their bereavement processes, a detailed user study and a more systematic measurement of user experiences should be conducted. Griever are sensitive users and tend to suffer from emotionally triggering questions, confusing interface or negative feedback. All of these aspects, on top of a precise and robust predictive model, should be heeded and monitored continuously.

# LUNCH

Dutch lunch can be culturally shocking and biologically challenging. LOL



Originally published in  
Oranje Express  
Nov 13, 2015

## Chapter 6 Discussion and Conclusion

Below we review the major findings/contributions of the project critically and reflect the lessons learned in the process. We look into the following four themes that summarize this dissertation's contribution in different aspects: insights into HCI fields, insights into psychology fields, ethical considerations and study design, and insights into administering an online questionnaire study on MTurk.

### 6.1 Insights into HCI field

In Chapter 3, we argue that technology is a mediator for many activities and offers access to various support resources. We further propose two opportunities for designing technology that support the bereaved in the early phase of bereavement, empowering decision-making and enabling meaningful activities. Based on our findings in Chapter 4 and 5, the empowerment process should precede the enabling process. Below we summarize and discuss the critical findings.

#### 6.1.1 More needs to fulfill in addition to attending the mental disorder

Our study in Chapter 3 uncovers many other potential needs that can be fulfilled through technology. These needs are also identified and studied by other researchers. For instance, dealing with the digital legacy [11-13, 194-196], seeking social support on the internet [55, 59, 297], making the dying process less suffering through technology [298, 299], and keeping the spiritual/emotional bonds with the deceased through social network [19, 20, 61].

Technologically-mediated bereavement activities are in general common but frequently limited to utilizing the personal devices and internet services. Many actions do not necessarily require technological mediation but have a potential to be mediated by technology. Take EtG

as an example, all of the questions can be administered through a paper-based questionnaire or psychotherapist. It is hard to determine which approach would be better to empower the griever's decision-making since the assessment is highly subjective due to different preferences, cultural background and using habits. However, EtG does offer much faster and more precise calculation on the predictive model, easy and wide access through connected devices, and scalability and potential to be integrated into a larger portal depending on the different phases of bereavement support. Furthermore, it is a relatively low commitment to gather necessary minimum information to make a critical decision in the beginning phase of bereavement. These reasons would support the necessity and benefit to have a support system like EtG, and so can HCI researchers identify various new experiences or benefits in developing other types of supportive technologies.

With the growing integration of technology and digital activities in our everyday lives, we can expect more and more bereavement needs being mediated through technology and varied experiences being introduced by utilizing popular technologies (e.g., VR and AR). A primary thought is that technology does not ostracize other means of bereavement support but should explore to work hand in hand with various resources. The reason is that there are needs that best served by technology (e.g., connectedness, responsiveness and preciseness) and needs that best supported by institutes, therapists or other resources (e.g., rituals, personalized counselling and social empathy). The following three aspects would benefit further design of technology in attending the needs of the bereaved:

- (1) the aspect that technology can perform outstandingly in offering support to the bereaved (e.g., organizing digital legacy and continuing bonds with the deceased on social networks)
- (2) the aspect that technology should be incorporated into other supportive processes (e.g., EtG or other technologically supported Cognitive Behavioral Therapy)
- (3) the aspect that should primarily be fulfilled by other supportive resources (e.g., treating suicidal ideation or the social support from other important figures)

Even though the third point does not always require technological solution, it still could benefit from its involvement. Since personal devices and internet are highly integrated in our everyday life activities, studying the needs of the bereaved contribute valuable insights in further design of more personalized and versatile bereavement support with technology.

#### 6.1.2 Conducting activities that will exhibit (positive) changes on the bereavement experiences

Our study diversifies griever's into two types, coping through the natural grief mechanism and



coping through the assistance of psychotherapy [33, 36]. Both types of coping strategy should be applied to the group that will benefit from them [121]. Therefore, the decision whether a clinical intervention is necessary should be made earlier with the expectation to lead to a personally meaningful outcome.

EtG is targeting on helping the bereaved to make clinically-related decision. Hence, it does so by providing a predicted probability of suffering from PGD and a suggesting message of whether the griever may benefit from professional intervention. From the pilot study (Chapter 4), we have observed grievers' confusion about whether they were grieving in a proper manner, and internet resources could provide a primary feedback that nudge further action. One of the critical components that facilitates empowerment, according to the empowerment model proposed by Cattaneo and Goodman (2010), is knowledge [169]. In our understanding and in the bereavement context, knowledge indicates the relevant information that supports the grievers' decision making process, disregarding from which resources the knowledge is gathered. From our studies, we also frequently observe individuals seeking advice or information from the internet, friends or professionals. In this regard, knowledge provided by EtG is the predicted probability of developing PGD in the long run (including the possible implication of this probability). It does not make the decision for the grievers, but inferring from our qualitative findings in Chapter 5, some grievers indeed realize that they need clinical support after using GIFT. This interaction pattern endorses the possibility of EtG supporting the clinically related decision making in the bereavement context. Although it is not within the scope of the study, the empowerment effect can be further validated by conducting a follow-up study to track their behaviors.

Considering that the bereaved report many needs except decision making, more convenient services can also be added to connect grievers with the necessary resource such as self-help websites or homepage of a psychotherapist. For instance, GIFT is designed to be a prototype for self-monitoring of grief experiences. With proper study and algorithm implementation, the app can provide sophisticated answers. If the system detects an individual having difficulty reconstructing meaning post-loss, some writing exercises can be suggested based on the meaning reconstruction therapy. What has been specifically implemented in GIFT is the suicidal detection function due to the ethical requirement of the IRB. The system tracks the users' answer in the questionnaire and immediately determine the location of the user to link to the suicidal hotline information page. More reactions in responding to a specific answer can make the system more intelligent and informative, but these responses require a close collaboration with psychotherapists and more insightful studies of the correlations between risk factors and coping strategies.

Carrying out the activities that are needed after making the decision to adopt a specific coping strategy is also critical since it is where the change will happen. Gaining a sense of self-efficacy is of significant value at the beginning of confronting the life challenges [168, 207] since it allowed the grievers to actively target on the aspects that can be managed by the individuals and sustain the effort of coping with the grief [98, 105, 164-167]. GIFT and EtG are similar in providing the necessary knowledge for decision making, which facilitates further empowerment process but are not directly intervening the empowerment and coping processes. There are more to be done in empowering the bereaved to self-monitor their bereavement and even cope with it. The possible directions are, but not limited to, providing suggestions to cope with risk factors, probing actions or reminders to work with grief, feeding personalized knowledge based on the grief experiences, monitoring the progress of coping activities, and connecting with the professionals to collaboratively administer therapy. Having a clinical psychologist in the team is of imperative importance for the development of a more "intelligent" and clinically useful system.

Although the bereaved are stakeholders of their bereavement processes and could take the responsibility to decide their coping activities, it does not necessarily mean that the bereaved need to go through the process alone and unsupported. Individuals are highly associated to the community and society to a certain extent that their activities, thoughts and emotions are interconnected with the community and the broader circle/network of human beings. Our project concentrates on the bereaved internet users, supporting the coping activities through internet is where technology can certainly intervene with its advantage of the fast and often free access to ample resources of stories, experiences and guidelines and the anonymous nature of testing and exchanging new thoughts and strategies without straining regular social relationship or compromising the existing self-identity [11, 17, 20, 55, 59]. The characteristic of self-efficacy is frequently regarded crucial for empowerment [300-303]. It could also imply that the feeling of losing control or not knowing what to do could disturb the bereaved's coping process. The other supporting figures, resources or technologies often act as facilitators that support the bereaved to regain self-efficacy and make the personally meaningful (note: in an alternative to the "right" or "best") decisions.

### 6.1.3 The bereaved's online empowerment experiences

The goal of empowerment in bereavement is to lead to a more personally-meaningful decision in coping with the grief since grief is a highly personal experience and the needs to cope with it could vary for different individuals. The decisions made could exhibit great impact on the coping result, as reported by the interviewees in Chapter 3. Therefore, offering a systematic decision architect to help the grievers find a desirable choice. The advantage of integrating the



empowerment thinking and predictive model is that the designers not only motivate the bereaved to take the stake but also ensure that the coping outcome would adhere to what the bereaved expect. Regarding the necessity to have technical interventions, the same statement applies to designing a self-management or self-monitoring PSS. Empowerment experience does not have to be mediated through technology, but considering the convenience, precision, accessibility and low commitment advantages provided by technology, it is only more advantageous to try to mediate empowerment experience through technology. Furthermore, burgeoning studies have supported the positive effect of utilizing a self-management PSS in the digital health (eHealth or Health 2.0) for the individuals [304-308].

The study result in Chapter 3 indicates that internet bereaved users frequently utilize internet to seek social support, read other grievers' stories, learn from grieving support resources and conduct their mourning activities. Chapter 4 and 5 investigate the participants' willingness and experiences to seek support on the internet. When GIFT was deployed in the pilot study (Chapter 4), three out of five participants indicated that they had experiences of searching for the information on the internet and reading others' stories of coping with grief. We then deployed GIFT through MTurk to collect data necessary for the predictive models building. Around 43% of the participants provide 271 pieces of spontaneous feedback to our system. Many participants indicate indirectly that they feel reinforced by the feedback and the questions are thought-provoking. Our study result has proved two points. First, the internet users can and are willing to be empowered through using an internet-based self-monitoring PSS. In fact, it was not the system itself that empowered the grievers, but the thought-provoking questions and feedback. It does not matter whether the questionnaires were administered through paper-based tests or internet-based PSS, as long as the questionnaires and feedback were well-designed, it can empower the participants. Second, it is even more suggestive to implement an Internet-based screening PSS rather than a paper-based questionnaire since the system can be more responsive to the potential risks (suicidal ideation), and provide a quick link to necessary, maybe also authentic, support resources. Furthermore, some participants wished to share the results with their other friends or family members or share their stories anonymously, which can be easily completed and programmed with technology but can be hard to implement physically (e.g., anonymity).

## 6.2 Insights into Psychology

### 6.2.1 The further narrow down of potential variables

Although the aim of the thesis is to develop a screening method (system) rather than validating

each risk factor, and some of our findings are inconsistent with previous studies, the approach of fitting three models can provide a good inference for potential covariates of PGD. The finding of this study validates 15 covariates of PGD out of 50 candidate variables. Also, our process of entering variables by group generates many insights into identifying the potentially significant covariates from less significant ones. For instance, most of the demographic variables are not supported by our study to be significant covariates of PGD in comparison to the risk factors. Some of the variables exhibit a reverse association to PGD from univariate logistic regression to multivariate logistic regression. This fact suggests that the variables might be protective factors when other risk factors are present.

### 6.2.2 Seven variables that exhibit high correlation to PGD

Seven proposed predictors (without considering the two conditional predictors) appear to demonstrate a high correlation to PGD based on evaluating the three models in Chapter 5. The criteria of identifying these factors are (a) being a significant predictor at  $p < .001$  level in the univariate analysis and (b) being a significant predictor in all of the model fitted (when added in a model, it never falls out of the group of significant predictors). The predictors that fulfill these criteria are (1) being a spouse or partner of the deceased, (2) history of mental illness pre-loss, (3) multiple concurrent losses/traumatic events, (4) feeling angry about the loss, (5) feeling empty or emotional numb post-loss, (6) difficulty reconstructing meaning post-loss, and (7) discovering the body. Age is excluded because it was added at the beginning but only started being a significant covariate in Model 2 and 3.

In our study, we attempted to sample as many types of bereavement as possible in hopes to extract the risk factors that were significant regardless of the types of bereavement. It is clear that some risk factors are only applicable to a particular type of bereavements, such as pre-death marital dependency or caregiver burden. The resulted seven variables should be viewed as the risk factors in most of the bereavement conditions. The implication is that these factors should be examined and added in the analysis due to their theoretical values for future studies.

### 6.2.3 Insignificant confirmed risk factors in the predictive model

Four out of six confirmed risk factors are not supported by our study (see Table 4.1 for the confirmed risk factors). The only two confirmed risk factors endorsed partially by our study are (1) being a spouse of the deceased and (2) discovering the body. Unsurprisingly, these two factors are also part of the seven strongest predictors discussed in the previous section. However, the four confirmed risk factors are excluded in all three models. There are three explanations for this inconsistent finding. First, some of the variables should be evaluated more thoroughly such as social support and attachment style. It could be invalid to measure these variables through a

single question. Furthermore, there might be more aspects of attachment style or social support that could specifically contribute to predicting PGD. Measuring these two variables with one or two questions could result in getting the surface level understanding of the real cause. Therefore, the study should be designed to measure the variables properly to ensure more perspectives are considered. Second, pre-death marital dependency can be only applicable to the spousal bereaved. One thing to note is that we have modified the question to only measure pre-death dependency on the deceased to make it applicable to different types of losses. The study result proved that a confirmed risk factor could be insignificant when implementing it on predicting the PGD among different types of griever. The third reason is that there are confounding variables. The example identified in our study is that neuroticism was not included, but history of mental illness appeared to be one of the seven strongest predictors across three models. The interesting thing is that neuroticism is regarded potential predictor of several bereavement-related mental illness such as Depression [283-285] and PTSD [286, 287], and the history of mental illness does exhibit a significant positive association with PGD. It indirectly suggested that the predictability of neuroticism should be carefully evaluated and history of mental illness could be the confounding variable.

#### **6.2.4 Predictors that are only significant risk factors under certain circumstances**

We have stressed the benefit of having different models to predict PGD and provided evidence that confirmed risk factors might not apply to every type of loss in the previous sections. More studies regarding specific risk factors in various types of losses are needed to contribute to more targeting predictive models. The example in the previous chapter is pre-death dependency, which might be valid only in the circumstance that the bereaved are in a marital relationship with the deceased. Therefore, when we fit the model without considering the condition, our result fails to support the validated factor.

It is highly possible that more conditional risk factors do exist, but to confirm their predictability require further empirical studies to provide theoretical validity and avoid ignoring the potential confounding variables. It is suggestive that future studies attempt to define control variables before examining the independent variables. Possible control variables could be ethnicity (which is controlled in our study, too), type of loss, or age.

### **6.3 Ethics Considerations and Study Design**

Plenty of ethical concerns can arise when we study the potentially clinically bereaved. The

definition of the prolonged griever indicates that they could suffer from severe yearning and social dysfunctions, and suicidal ideation. Here we address two tensions, the potential to induce suicidal ideation and the risk of experiencing severe emotional distress after participating in the study.

Regarding the first tension, special attention was placed on questions asking about the suicidal ideation, since a potential ethics concern could arise, whether asking about suicide and related behaviors could induce suicidal ideation. The study of Dazzi et al. (2014) suggested quite oppositely, talking and acknowledging about suicide might reduce the ideation. In the case of EtG, even though the study indicated that suicidal ideation might not be enhanced or induced through asking relevant questions, we still programmed the warning notice for users showing a certain level of suicidal ideation. It is only suggestive for the researchers in the bereavement studies that suicidal ideation should be cautioned.

However, the ethics tension we intend to address is how to gather the data with empathy to the potentially clinically bereaved individuals. In the last two studies, we administered the app with feedback at the end of each questionnaire. Providing feedback does not necessarily contribute to the study, except sustaining the participant's interests and prompting them to share their experiences with us. The feedback feature makes the data collection system slightly different from the ones administered by other studies such as Qualtrics, Google forms, or surveyMonkey. Based on this experience of conducting a sensitive survey of the internet, this slightly innovative approach of gathering a questionnaires data is regarded user-centered and positively experienced by the participants. The potential challenges are that developing process can be lengthier and the feedback provided to the participants could also raise ethical concerns. We have made this conscious choice being more inclined to satisfy the user-centered design requirements. It is up to the researchers to weight the pros and cons of designing a system like GIFT and utilizing it as a data collection tool.

### **6.4 Insights into administering an online questionnaire study on MTurk**

Recruiting participants to answer the questionnaires can be challenging for many researchers, and administering questionnaire studies on the internet has become an inexpensive and efficient alternative. MTurk is one of the platforms that allow researchers to recruit a decent number of participants for their studies with a relatively low cost. Previous literature has supported MTurk's potential as an inexpensive platform to gather quality data [250, 251, 288], but also indicated that

the quality of data gathered relies heavily on the study and system design. Here we present some insights garnered from conducting the GIFT deployment study through MTurk.

#### 6.4.1 The necessary functions to be included in the program

*Check the overall start time and end time.* In the study presented in Chapter 5, we recorded the start time and ended time of each questionnaire and of the whole session of answering all questionnaires. The time we have noted become a standard of checking which participants might click through and which participants were carefully answering the questions. The process of approving the Turkers' answer has proven that time is a very effective indicator of quality data (we checked it with the timestamps stored in MySQL database). For instance, if a participant only spends less than one minute on a questionnaire that mostly requires four minutes, it is very likely that the participant is clicking through and the data could be questionable. MTurk also provides a similar function, but it measured the time participants accepted the task until they submitted the completion code. Some participants tend to schedule several tasks together, and it results in false perceptions that they could spend more than 10 hours doing the task. Therefore, a system record is more suggestive for the researchers who need quality data.

*Program several attention checkers and provide immediate warning.* Attention checker is a favorite way to evaluate if participants are answering the questions seriously [248, 288, 309-311]. However, Qualtric (an online questionnaire system that is frequently utilized with MTurk) also post an article warning the potential harms of using attention check [312]. From our pilot study of GIFT in Chapter 4, grievors are easily triggered and annoyed by any inappropriate wordings, repetitive questions or weird questions. Therefore, the attention checkers we programmed were based on some common mistakes we identified by administering the questionnaires to pilot testers. For instance, one of the questions asked about the user's relationship with the deceased. The answer was often opposite. Participant clicked on being a "grandma" of the deceased, but he was the grandson of the deceased. For the complete attention checkers, please refer to the details in Chapter 5.

In our case, attention checkers should be programmed in the way that they would warn the participants rather than discontinue the study because we wish to gather quality data rather than rejecting participants due to misunderstanding the questions. The chance that participants lied about experiencing the death of a loved one is unknown, but considering the large (and maybe quality) amount of data the researchers could gather by clarifying the potential misunderstandings in a questionnaire, it is much worth letting the participants be aware of the potential answers that might fail them.

*Store each entry of the questionnaire answer separately.* Each entry of questionnaire answer is

stored as a new row of data in the MySQL table. It allows the researchers to keep a clear track of any changes users might make on their answers. The way to differentiate each entry is to store the complete answers in the database when the user clicks "submit" button. The next time user submits an answer, it should be stored as a different entry. In this way, we successfully identified two participants who might be lying by changing their answers to fit the study requirements.

*Create a personal session with MTurk ID.* Unlike the other online questionnaire systems that only allow participants to answer the questionnaires once, we intend to allow participants to log in several times and review their progress or continue where they left in the study. Considering that we implement nine questionnaires in GIFT, and our participants easily decide to discontinue if the system annoys them. Storing the in-progress data can be critical to avoid losing data and confusing the participants. Asking users to create an account is a severe violation of MTurk's policy, and it resulted in our task being reported and discontinued. We later modified the system to require MTurk ID, which is an alternative "ID" that Amazon allowed requesting in the task. Surprisingly, some of the participants also tried to self-censor their MTurk ID by mixing uppercase and lower cases in their MTurk ID (usually MTurk ID is created with capital letters). Other participants accidentally copied a white space, causing problems to login with their "correct" MTurk ID. Researchers should consider removing the space and capitalizing all the letters with the following commands:

For javascript

```
function processID(input) {
    return input.toUpperCase().replace(/\s/g, "");
}
```

For PHP

```
function processID($input) {
    return strtoupper(preg_replace('/\s/g', '', $input));
}
```

*Add a completion code.* Completion code does not reflect the quality of data but is evidence that the participants made it to the last step. It is suggestive that the completion code for each Turker is unique so that the researchers can confirm the completion of each participant. We programmed it using md5 hash function and stored the completion code together with the MTurk ID in the same row in the database. Participants were only allowed to generate the completion code once, and once a participant generated a completion code, a system notice will be sent to the system administrator's mailbox with the MTurk ID and the completion code combination. When the participants reported the code on the MTurk portal, the researchers could easily check their ID and the completion code pair from the system notice email.

### 6.4.2 Recap: steps to evaluate the answers

To sum up, administering an online questionnaire study on MTurk can be an efficient and inexpensive manner to gather a significant amount of data within a short period. Here we present several steps derived from our study that could help other researchers to evaluate the answers successfully. Note that these steps can be programmed in the system to have them automatically checked.

- Check the entries in the database to confirm how many times the participants have made changes on their data and identify potential lying participants.
- Check the overall completion time.
- Check if any attention checkers are activated.
- Check the match of completion code and MTurk ID.
- Decide if the submitted HIT (Human Intelligence Task) will be approved or rejected. In case of rejection, provide proper reasoning based on the previous four steps.

## 6.5 Conclusion

This thesis reports our design through research project that aims to develop an internet-based screening method that can contribute to empowering the bereaved regarding the decision of whether a clinical intervention is needed in the first six months of bereavement. Our research objective is motivated by the necessity to determine who will benefit from the bereavement intervention [121] and the final deliverable requires us to translate the psychological insights into an internet-based PSS that can be directly used and understood by the bereaved internet users.

We begin by inquiring the role technology plays in the bereavement process to understand the bereaved internet users' needs that can potentially be or are already attended by technology. Activity is regarded a critical trajectory that allows technology to mediate our everyday life experiences and well-being [132, 159, 173, 174, 177, 180]. Targeting on the activities the bereaved intentionally conducted to cope with the bereavement, we identified 11 activities that could potentially be or were mediated by technology. The further discussion of the findings prompted us to focus on developing a technology that can contribute to empowering the bereaved internet users.

Our second inquiry was how to gather the necessary data to support building the predictive model of PGD in the first six months of bereavement. An internet-based data gathering system, Grief Inquiries Following Tragedy (GIFT), was designed to gather the questionnaires data related to three groups of variables, background factors, bereavement risk factors and

bereavement outcome factors (factors are derived from field practices and the reviews of Burke & Neimeyer, 2013; Lobb *et al.*, 2010; Stroebe *et al.*, 2006) [128, 129, 218].

In the last phase, we questioned about how to design the screening method that offers meaningful feedback to empower the bereaved internet users' decision-making regarding whether a clinical intervention is needed. GIFT was deployed through MTurk, and the data gathered was implemented to fit three predictive models for comparison. The selected model was fitted mostly with bereavement risk factors, proving that bereavement risk factors are the best predictors of PGD in the early phase of bereavement.

Our final deliverable is an internet-based PSS, Empowered to Grieve (EtG), that is based on an empirically validated PGD predictive model and demonstrates a potential to contribute to empowering the clinically-related bereavement decision-making. To date, we have not identified any other internet-based applications that yield the same function, and this research is believed to be one of the forerunners in developing a screening method and successfully translating the psychological insights into a usable and widely accessible application for lay users (grievors).





Dutch weather is notoriously bad, especially in winter.

It is as capricious as women.



## WEATHER

Cycling in the hauling wind and stormy weather is like a daily routine in the Netherlands.

Fun Dutch facts Vol 7



Originally published in  
Oranje Express

Jan 8, 2016

## Chapter 7 Reflections, Limitations and Future Work

### 7.1 Reflections

All of the design implications were presented in the previous chapters, and here we further summarize some of the considerations that could work as starting considerations for the system conceptualization and should be revisited several times during the design processes to ensure that the system is design with thoughtfulness and sensitivity.

*Acknowledge that the bereaved have “tried their best”*

It is normal for the bereaved to constantly *bargain* with the reality. The phenomenon happens not only in possessing the wishful thinking of “what if” in regards to the situation the deceased died, but also when making decisions regarding the end of life and coping activities. It could be related to a feeling of guilt and regret. The study reported in Chapter 3 indicated many examples of guilt and regret feelings because the griever believed that their decision could lead to a different outcome *if* they did or did not do something. The system should acknowledge that the bereaved have already made the decision by trying their best even if the result might not be satisfactory. It is rare that the result will be satisfactory in a bereavement context. People could feel sorry and regret to a certain extent. Therefore, when designing for empowering decision-making, the designers should try to acknowledge that there are no *best* decisions but the decision made by *trying the best* of the bereaved.

*A different perspective on power and gaining power*

The process of empower involves gaining power, but power can be interpreted in a variety of manners depending on the different contexts. In the bereavement context, the power should be interpreted as the resilience and tenacity to remain hopeful and sustain the self while the meanings of the bereavement gradually unfold. Power is the wisdom to embrace the sadness with

hope of experiencing joy again and the courage to re-love the world and life despite the loved one is no longer physically present. In comparison to the traditional belief of masculine power and thorough control of the situation, knowing the limit of self, taking time to revisit and process the distress and finding the hope to sustain the love to the world are more coherent with what the bereaved would interpret as the strength needed to pull through the situation. The process of empowerment, or gaining power, should be a process of self-accepting, re-learning the meaning, and gaining hope, courage or resilience to face the life without a loved one.

This does not suggest that the system should disregard the design related to self-management or control, but to implement the idea with taking the above discussion of power into consideration. How would this be manifested in a system? This concept is similar to the DPM, acknowledging that both restoration-oriented and loss-oriented response could have important implications to the bereavement process, and the system design should make it explicit in a meaningful manner. If the system tries to display a bar chart of the grief score, make each phase meaningful by reinterpreting the scores. For instance, the higher score means that one is courageous to hold onto the relationship despite the agony, and the lower score means that one has allowed joy to reside within the tragic context.

*Be sensitive to the possible emotional responses*

The bereaved often experience emotional responses during the process of reminiscing. It is expected that the bereave would also experience emotional moments when using the app. In fact, we also observed emotional moments in our studies. It is important for the system to inform the bereaved that this kind of situation *might* happen and to save the progress in case of abruption caused by emotional responses.

*A hidden progress bar for coping with bereavement*

The old saying that “*time will heal all wounds*” leads to a misperception that grief will recede over a certain period, and fails to acknowledge the (mental or behavioral) effort one needs to commit. However, from the perspective of the bereaved, knowing that the pain will be pacified eventually can be critical in sustaining the effort of pulling through each day and coping with the grief. Taking the design scenario as an approach to understand the phenomenon, it is a universal principle of implementing a “progress indicator” on the interface to inform users about the current status of the system (percent of data loaded). In the situation that the system is functioning slowly or needs a longer buffering period, progress indicator is highly important to make the process less insufferable. The concept of a progress indicator is not only applied to design context, but also frequently adopted in different fields of practice and is the core of self-monitoring .

It is not practical to design a progress bar for one’s bereavement process as we see how linear bereavement models were criticized by the researchers. However, feeling disoriented is a

common experience of many grievors. Knowing that they are making progress in the seemingly overwhelming distress and the period of coping can be very motivating. Furthermore, the bereaved also need to know that there will be an end to the agony in the future. Therefore, design that tactically endorse a progress concept, or a monitoring feature could be especially helpful in sustaining the hope and enhancing the engagement of coping.

## 7.2 Evaluate EtG in terms of the thoughtfulness of the technology

Consider how HCI researchers place immense effort to integrate psychological insights into computer and human interaction, insights derived from psychology and user studies are frequently highly informative and inspirational for a more user-friendly and user-centered technology design. In this project, we collaborated with clinical psychologists and studied users' feedback to make the technology more usable and (thoughtfully) empowering.

EtG is an internet-based web application designed to explore the opportunities of empowering the bereaved in the early phase of bereavement. Judging from the functions of EtG, it clearly adheres to the principle of motivating a personally meaningful goal (decide whether a clinical treatment is needed) [169], which might hopefully lead to further action to complete the goal. However, in the current form of EtG, it would have a limited contribution to empower the bereaved since it does not incorporate the broader level of scope (societal level of empowerment). The feedback from our participants also clearly endorsed this potential. To empower the users more thoughtfully, EtG would have to incorporate a broader scope of defining the personally meaningful goal(s) and engaging the community resources. To enhance the relevancy of EtG to the bereaved, it is important to plan a larger scale context or portal that can host professional bereavement support resources, including EtG. We use EtG as an example to elaborate where the technology designer begins to approach the purpose of thoughtful empowerment and how the abovementioned criteria allow the researcher to further map the development of the technology.

## 7.3 Limitations

### 7.3.1 Assessing the effect of empowerment

One of our main contributions is the predictive model of PGD within the first six months of bereavement that has been empirically studied and is implemented on an internet-based web application. Our studies reported in Chapter 4 and 5 also showed that participants would be

inclined to accept the suggestions provided by GIFT. The insufficient part is that there was no follow-up study to assess the effect of empowerment due to the time limitation of the research project. However, the effect of empowerment could be inferred from the qualitative results of the study and it did not interfere the model fitting, which was the major study goal of the third study. Further studies for validating the empowerment effect with different recruiting channels (rather than MTurk) will certainly help to strengthen our initial positive findings.

### 7.3.2 Study samples

All of the studies included in this thesis have a major portion of participants from western culture. In the last two studies, we recruited 99% of participants from the USA, which suggested that the study results would currently be best applicable to the bereaved individuals who have their culture identity towards Western culture, especially USA culture. The bereavement responses in the normative belief and rituals after death of loved ones can vary depending on the culture, and the differences caused by culture should also be disclosed explicitly to avoid misinterpretation of the result. The result should be interpreted with caution and more intercultural studies would certainly be beneficial.

### 7.3.3 Require a longitudinal study for further validation

To strengthen our findings, a longitudinal study can be the next step. The regression model presented in our study is built with contemporaneous data due to the limitation of time in the project. We try to compensate this pitfall by including the relatively static factors that can be monitored before and after six months' time point of the bereavement. There are two reasons for recruiting participants who have bereaved for more than six months but less than five years. First, the study targets on identifying participants who screen positive with PG-13, and PG-13 is particularly used to screen PGD individuals after six months of bereavement. Second, the risk factors suspected by the review papers can be up to 50 variables, and some could be confounding variables. Before conducting a longitudinal study, it is necessary for the researchers to clarify which variables demonstrate higher correlation. In other words, this study can serve as a pilot study for the future longitudinal validation. Limiting the scope to collecting data from a maximum five years before is because after this period, the memory become less accurate. Although a longitudinal study is not planned given the limited timeframe and scope of the research project, our findings have contributed the critical aspects for the longitudinal studies in the future.



## 7.4 Future Work

### 7.4.1 Future work on the screening model

As we have discussed in section 7.2.3, a longitudinal study is necessary to validate the risk factors and predictive model in our study. Another aspect that will benefit from a longitudinal study is to track the effect of empowerment and its long-term impact. How many of the bereaved users have accepted the suggestions on GIFT? Does accepting the suggestions impact their coping outcomes? What factors are risk factors that predict PGD? More studies that include pre-loss and post-loss bereavement process will help to provide further validation of the study results.

### 7.4.2 Future work on EtG

EtG is an approach to explore how internet-based web application can be utilized to both conduct the bereavement-related study in a more benevolent and ethically responsible manner and empower the bereaved through nudging the clinically-related decision-making. To make EtG really usable and useful for the bereavement context, building a mature and versatile portal for different types of bereavement support is highly important. The aspects that require further considerations are discussed below.

#### *More innovative interaction experiences of using EtG*

Deploying a questionnaire on the internet through a web portal is a very popular and frequently used data gathering method for researchers. However, the new insights for an innovative interaction experience generated through the process are limited. For HCI researchers who look into innovating the interactive experiences, a more innovative interaction experiences for empowering the bereaved should be of interest for further development. Considering more technologies are introduced such as Arduino, Augmented Reality (AR) and Virtual Reality (VR). The interactions between a PSS and users do not have to be limited to clicking answers and viewing the feedback. Popular implementations could include, but are not limited to, wearable sensors for the activity monitoring, VR and AR integration of the data gathering processes or the interventions, using personal devices to further validate the effect of the empowerment and many more personalized bereavement interventions that can be enabled by self-learning algorithm. It requires more creativities and knowledge of users' needs and experiences to explore their application in different fields and the new interactive patterns with them. With so many opportunities unfolded by the new technology, researchers and designers can certainly make good use of it and target on creating various innovative interaction experiences to empower the bereaved.

#### *Long-term monitoring of the empowerment effect*

Empowerment should be viewed as a process, and so is monitoring. It requires a longer term of track keeping and data gathering to evaluate the effect. The current function of EtG was to provide immediate feedback based on the answer at the moment. However, to make EtG more applicable to the bereavement context, a long-term process monitoring would be very beneficial. Self-reflection is one of the critical factors of the empowerment process, and not allowing the individuals to reflect on the effect would render the empowerment initiative futile. The developers of EtG should implement functions such as the visual feedback such as line chart or bar chart to display the long-term effect of the bereavement process, and allow users to interact with the chart to review their progress.

#### *Providing more sophisticated suggestions*

The predictive model of EtG is straightforward currently. It receives data from the user and performs the calculation of the predicted probability and then provides feedback. A bereavement process is highly personal and complex. If EtG would be implemented in a real-life context, it would have to be "smarter" in responding to different phases of bereavement needs and providing more personalized and sophisticated suggestions. For instance, for users who answer that they might suffer from discovering the body, EtG could suggest the method such as meditation and redirecting the attention. It should also allow the users to predict the outcome of conducting a certain coping activities and reflect on the effect of following the suggestions. A more sophisticated algorithm is necessary to respond to a variety of bereavement needs and customize the best suggestions for the griever.

#### *Link to more supportive resources*

The most ideal scenario of supporting the bereaved is when the system and the clinical practitioners can work hand in hand to provide fast and accessible screening and more personalized and professional treatment. Since EtG is developed for all of the griever, it would be beneficial to link griever to further supportive resources should they need any. The examples of supportive resources should be divided into two groups: normal griever and PGD griever. For normal griever, they could benefit from more useful reading materials, online forums or general information about grief process. For the PGD griever, a location based search for therapists and immediate access to emergency support should be prioritized in addition to the other materials.

### 7.4.3 Future work on the bereavement-related studies

#### *Targeting treatments*

Studying the risk factors allows the researchers to narrow down the possible symptoms that can be induced by experiencing a certain type of risk factor(s). As we have learned from the previous

studies and literature, interventions that do not target on the clinical bereavement symptoms could fail to warrant a positive treatment effect and hamper the bereavement process [45-47]. Offering a more targeting intervention can also make use of the supporting resources prudently.

To design a more targeting intervention would require a deeper understanding on the risk factors and the different types of symptoms that could occur provided certain risk factors are present. More careful examination on each risk factor validated through our study and the association with the various PGD symptoms is highly recommended.

#### *Indicated preventive interventions*

To date, there has not had effective ways of providing interventions for PGD symptoms and impairment in the first six months of bereavement [9]. Therefore, a most straight forward future research opportunity that is associated with the predictive model is the development and validation of preventive intervention for PGD in the early phase of bereavement. Building an effective screening method is one of the corner stone towards developing preventive interventions. Although more studies with more specific groups of grieverers are certainly required to further examine the model maturity, it does indicate that the researchers could have a primary understanding of the expected long-term development of the grief severity in the early phase of bereavement.

More questions also arise with the development of preventive interventions. For instance, are the validated PGD treatments equally applicable when they are applied in the preventive context? Will providing preventive intervention accelerate the pace of returning to normal life functioning or shorten the bereavement period? When will be the golden window to receive best effect of preventive intervention? These are all interesting and potential future directions for research and development.



## References

- [1] Walter T, Hourizi R, Moncur W, Pitsillides S. Does the internet change how we die and mourn? Overview and analysis. *OMEGA-Journal of Death and Dying*. 2012;64(4):275-302.
- [2] Massimi M, editor *Thanatosensitively designed technologies for bereavement support*. CHI'10 Extended Abstracts on Human Factors in Computing Systems; 2010: ACM.
- [3] Massimi M, Charise A. Dying, death, and mortality: towards thanatosensitivity in HCI. CHI '09 Extended Abstracts on Human Factors in Computing Systems; Boston, MA, USA. 1520349: ACM; 2009. p. 2459-68.
- [4] Prigerson HG, Maciejewski PK, Reynolds CF, Bierhals AJ, Newsom JT, Fasiczka A, et al. Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*. 1995;59(1-2):65-79.
- [5] Shear K, Shair H. Attachment, loss, and complicated grief. *Developmental psychobiology*. 2005;47(3):253-67.
- [6] Maciejewski PK, Maercker A, Boelen PA, Prigerson HG. "Prolonged grief disorder" and "persistent complex bereavement disorder", but not "complicated grief", are one and the same diagnostic entity: an analysis of data from the Yale Bereavement Study. *World Psychiatry*. 2016;15(3):266-75.
- [7] Wagner B, Knaevelsrud C, Maercker A. Post-Traumatic Growth and Optimism as Outcomes of an Internet-Based Intervention for Complicated Grief. *Cognitive Behaviour Therapy*. 2007;36(3):156-61.
- [8] Wagner B, Maercker A. A 1.5-year follow-up of an internet-based intervention for complicated grief. *Journal of Traumatic Stress*. 2007;20(4):625-9.
- [9] Wittouck C, Van Autreve S, De Jaegere E, Portzky G, van Heeringen K. The prevention and treatment of complicated grief: A meta-analysis. *Clinical psychology review*. 2011;31(1):69-78.
- [10] Shear K, Frank E, Houck PR, Reynolds CF. Treatment of complicated grief: a randomized controlled trial. *Jama*. 2005;293(21):2601-8.
- [11] Maciel C, editor *Issues of the social web interaction project faced with afterlife digital legacy*. Proceedings of the 10th Brazilian Symposium on Human Factors in Computing Systems and the 5th Latin American Conference on Human-Computer Interaction; 2011: Brazilian Computer Society.
- [12] Paul-Choudhury S. Digital legacy: the fate of your online soul. *New Scientist*. 2011;210(2809):41-3.
- [13] Maciel C, Pereira VC. *Digital legacy and interaction: post-mortem issues*: Springer Science & Business Media; 2013.
- [14] Thomas L, Briggs P. An older adult perspective on digital legacy. Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational; Helsinki, Finland. 2639485: ACM; 2014. p. 237-46.
- [15] Socolovsky M. Cyber-spaces of grief: online memorials and the Columbine high school shootings. *JAC*. 2004;467-89.

- [16] Veale K. FCJ-014 Online Memorialisation: The Web As A Collective Memorial Landscape For Remembering The Dead. *The Fibreculture Journal*. 2004;3:1-18.
- [17] Carroll B, Landry K. Logging on and letting out: Using online social networks to grieve and to mourn. *Bulletin of Science, Technology & Society*. 2010;30(5):341-9.
- [18] Maddrell A. Online memorials: The virtual as the new vernacular. *Bereavement Care*. 2012;31(2):46-54.
- [19] Getty E, Cobb J, Gabeler M, Nelson C, Weng E, Hancock J, editors. I said your name in an empty room: grieving and continuing bonds on facebook. *Proceedings of the SIGCHI Conference on human factors in computing systems*; 2011: ACM.
- [20] Kasket E. Continuing bonds in the age of social networking: Facebook as a modern-day medium. *Bereavement Care*. 2012;31(2):62-9.
- [21] Hutchings T. Wiring death: Dying, grieving and remembering on the internet. *Emotion, identity and death: Mortality across disciplines*. 2012:43-58.
- [22] Horowitz MJ. Stress response syndromes: PTSD, grief, and adjustment disorders: Jason Aronson; 1997.
- [23] Parkes CM, Prigerson HG. *Bereavement: Studies of grief in adult life*: Routledge; 2013.
- [24] Kübler-Ross E. *On death and dying*. New York: Simon and Schuster; 1969.
- [25] Kübler-Ross E, Kessler DA. *On grief and grieving: Finding the meaning of grief through the five stages of loss*. New York: Simon and Schuster; 2007.
- [26] Holmes TH, Rahe RH. The social readjustment rating scale. *Journal of psychosomatic research*. 1967;11(2):213-8.
- [27] Mash HBH, Fullerton CS, Ursano RJ. Complicated grief and bereavement in young adults following close friend and sibling loss. *Depression and anxiety*. 2013;30(12):1202-10.
- [28] Bonanno GA. *The Other Side of Sadness: What the New Science of Bereavement Tells Us about Life After Loss*. New York: Basic Books; 2009.
- [29] Ryan RM, Deci EL. On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual review of psychology*. 2001;52(1):141-66.
- [30] Vittersø J, Søholt Y. Life satisfaction goes with pleasure and personal growth goes with interest: Further arguments for separating hedonic and eudaimonic well-being. *The Journal of Positive Psychology*. 2011;6(4):326-35.
- [31] Lyubomirsky S. *The myths of happiness: What should make you happy, but doesn't, what shouldn't make you happy, but does*. England: Penguin Group US; 2013.
- [32] Bonanno GA, Kaltman S. Toward an integrative perspective on bereavement. *Psychological Bulletin*. 1999;125(6):760-76.
- [33] Bonanno GA, Kaltman S. The varieties of grief experience. *Clinical psychology review*. 2001;21(5):705-34.
- [34] Bonanno GA, Papa A, O'Neill K. Loss and human resilience. *Applied and Preventive Psychology*. 2002;206:193-206.
- [35] Bonanno GA, Wortman CB, Lehman DR, Tweed RG, Haring M, Sonnega J, et al. Resilience to loss and chronic grief : A prospective study from preloss to 18-months postloss. *Journal of Personality and Social Psychology*. 2002;83(5):1150-64.
- [36] Bonanno GA. Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *The American psychologist*. 2004;59(1):20-8.
- [37] Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of traumatic stress*. 1996;9(3):455-71.
- [38] Tedeschi RG, Park CL, Calhoun LG. *Posttraumatic Growth: Positive Changes in the Aftermath of Crisis*: Taylor & Francis; 1998.
- [39] Westphal M, Bonanno GA. Posttraumatic growth and resilience to trauma: Different sides of the same coin or different coins? *Applied Psychology*. 2007;56(3):417-27.
- [40] Ramos C, Leal I. Posttraumatic growth in the aftermath of trauma. *Psychology, Community & Health*. 2013;2(1):43-54.
- [41] Neimeyer RA. Meaning reconstruction & the experience of loss. Neimeyer RA, editor. Washington, DC, US: American Psychological Association; 2001a. xiii, 359 p.
- [42] Neimeyer RA, Levitt H, Snyder CR. Coping and coherence: A narrative perspective on resilience. *Coping with stress*. 2001b:47-67.
- [43] Holland JM, Currier JM, Neimeyer RA. Meaning reconstruction in the first two years of bereavement: The role of sense-making and benefit-finding. *Omega-Journal of Death and Dying*. 2006;53(3):175-91.
- [44] Neimeyer R, editor *Grief therapy and meaning-reconstruction*. Workshop presented at the Annual Convention of the American Psychological Association, San Diego, CA; 2010.
- [45] Allumbaugh DL, Hoyt WT. Effectiveness of grief therapy: A meta-analysis. *Journal of Counseling Psychology*. 1999;46(3):370-80.
- [46] Neimeyer RA, Currier JM. Grief therapy evidence of efficacy and emerging directions. *Current Directions in Psychological Science*. 2009;18(6):352-6.
- [47] Stroebe W, Schut H, Stroebe MS. Grief work, disclosure and counseling: Do they help the bereaved? *Clinical Psychology Review*. 2005;25(4):395-414.
- [48] Association AP. *Diagnostic and statistical manual of mental disorders (DSM-5®)*: American Psychiatric Pub; 2013.
- [49] Prigerson H, Horowitz M, Jacobs S, Parkes C, Aslan M, Raphael B, et al. Field trial of consensus criteria for prolonged grief disorder proposed for DSM-V. *PLoS Medicine*. 2009;6:1-22.
- [50] Shear K, Shair H. Attachment, loss, and complicated grief. *Developmental psychobiology*. 2005;47(3):253-67.
- [51] 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.
- [52] Prigerson HG, Vanderwerker LC, Maciejewski PK. A case for inclusion of prolonged grief disorder in DSM-V. 2008.
- [53] Guarnerio C, Prunas A, Della Fontana I, Chiambretto P. Prevalence and comorbidity of prolonged grief disorder in a sample of caregivers of patients in a vegetative state. *Psychiatric quarterly*. 2012;83(1):65-73.
- [54] Maercker A, Lalor J. Diagnostic and clinical considerations in prolonged grief disorder. *Dialogues in clinical neuroscience*. 2012;14(2):167.
- [55] Vanderwerker LC, Prigerson HG. Social support and technological connectedness as protective factors in bereavement. *Journal of Loss and Trauma*. 2004;9(1):45-57.
- [56] 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):359-67.
- [57] Kryszinska K, Andriessen K. On-Line Support and Resources for People Bereaved through Suicide: What Is Available? *Suicide and Life-Threatening Behavior*. 2010;40(6):640-50.
- [58] Kryszinska K, Andriessen K. *Suicide bereavement online: Sharing memories, seeking support, and exchanging hope*. *Suicide Prevention and New Technologies*: Springer; 2013. p. 150-65.
- [59] Massimi M, editor *Exploring remembrance and social support behavior in an online bereavement support group*. *Proceedings of the 2013 conference on Computer supported cooperative work*; 2013: ACM.
- [60] Sofka CJ. Adolescents, technology, and the internet: Coping with loss in the digital world. *Adolescent encounters with death, bereavement, and coping*. 2009:155-73.
- [61] James L. Continuing bonds in a virtual world: The use of Facebook in adolescent grief: Colorado State University; 2014.
- [62] Moncur W, Kirk D, editors. *An emergent framework for digital memorials*. *Proceedings of the 2014 conference on Designing interactive systems*; 2014: ACM.
- [63] Riechers A. The persistence of memory online: Digital memorials, fantasy, and grief as entertainment. *Digital Legacy and Interaction*: Springer; 2013. p. 49-61.
- [64] Bambuck M. *Online Funerals a Growing Trend?* ABC News. 2007.
- [65] *Lazy millennials are now attending funerals online*. New York Post. 2017.
- [66] Wagner B, Knaevelsrud C, Maercker A. Internet-based treatment for complicated grief: Concepts and case study. *Journal of Loss and Trauma*. 2005;10(5):409-32.
- [67] Wagner B, Knaevelsrud C, Maercker A. Internet-based cognitive-behavioral therapy for complicated grief: a randomized controlled trial. *Death studies*. 2006;30(5):429-53.
- [68] She WJ, Rauterberg M, Hu J. Identify the Activity-based Technology Design Opportunities in the Bereavement Context.

- [69] She WJ, Burke L, Neimeyer RA, Roberts K, Lichtenthal W, Hu J, et al., editors. Toward the Development of a Monitoring and Feedback System for Predicting Poor Adjustment to Grief. Proceedings of the Conference on Design and Semantics of Form and Movement-Sense and Sensitivity, DeSForM 2017; 2017: InTech.
- [70] Freud S. Mourning and melancholia. In: Strachey J, editor. Standard edition of the complete psychological works of Sigmund Freud. London: Hogarth Press; 1917. p. 152-70.
- [71] Lindemann E. Symptomatology and management of acute grief. *American Journal of Psychiatry*. 1944;141-8.
- [72] Bowlby J. Attachment and loss: Separation: Anxiety and anger. 2 ed. London: Basic Books; 1976.
- [73] Bowlby J. Separation anxiety: A critical review of the literature. *Journal of Child Psychology and Psychiatry*. 1960;1(4):251-69.
- [74] Bowlby J. Loss: Sadness and Depression. New York: Basic Books; 1982.
- [75] Hazan C, Shaver PR. Romantic love conceptualized as an attachment process *Journal of Personality and Social Psychology*. 1987;52(3):511-24.
- [76] Hazan C, Shaver PR. Attachment as an organizational framework for research on close relationships. *Psychology Inquiry*. 1994;5(1):1-22.
- [77] Bowlby J, Parkes CM. Separation and loss within the family. In: Anthony EJ, editor. The child in his family. New York: Wiley; 1970. p. 197-216.
- [78] Wiseman RS. Crisis theory and the process of divorce. *Social Casework*. 1975.
- [79] Crosby JF, Gage BA, Raymond MC. The grief resolution process in divorce. *Journal of Divorce*. 1983;7(1):3-18.
- [80] Oppawsky J. Utilizing children's drawings in working with children following divorce. *Journal of divorce & remarriage*. 1991;15(3-4):125-42.
- [81] Bakermans-Kranenburg MJ, van IJzendoorn MH. Adult attachment and the break-up of romantic relationships. *Journal of Divorce & Remarriage*. 1997;27(3-4):121-39.
- [82] Wortman CB, Silver RC. The myths of coping with loss. *Journal of consulting and clinical psychology*. 1989;57(3):349.
- [83] Bonanno GA. The other side of sadness: What the new science of bereavement tells us about life after loss: Basic Books; 2010.
- [84] Worden JW. Grief counseling and grief therapy: A handbook for the mental health practitioner: springer publishing Company; 2008.
- [85] Worden JW. Grief counselling and grief therapy: a handbook for the mental health professional. London: Routledge; 1991.
- [86] Thompson N. Loss and grief: A guide for human services practitioners. England: Palgrave Macmillan; 2002.
- [87] Stroebe M, Schut H. The dual process model of coping with bereavement: Rationale and description. *Death Studies*. 1999;23(3):197-224.
- [88] Davis CG, Nolen-Hoeksema S, Larson J. Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*. 1998;75(2):561-74.
- [89] Klass D, Silverman PR, Nickman S. Continuing bonds: New understandings of grief: Taylor & Francis; 2014.
- [90] Neimeyer RA, Baldwin SA, Gillies J. Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death studies*. 2006;30(8):715-38.
- [91] Keltner D, Bonanno GA. A study of laughter and dissociation: distinct correlates of laughter and smiling during bereavement. *Journal of personality and social psychology*. 1997;73(4):687.
- [92] Wortman CB, Silver RC. The myths of coping with loss. *Journal of consulting and clinical psychology*. 1989;57(3):349-57.
- [93] Wortman CB, Boerner K. Beyond the myths of coping with loss: Prevailing assumptions versus scientific evidence. *The Oxford Handbook of Health Psychology*. New York: Oxford University Press; 2011. p. 438-76.
- [94] Stroebe M, Schut H. The dual process model of coping with bereavement: A decade on. *OMEGA-Journal of Death and Dying*. 2010;61(4):273-89.
- [95] Archer J. The nature of grief: The evolution and psychology of reactions to loss: Routledge; 2003.
- [96] Elias N. Loneliness of the Dying: Bloomsbury Publishing; 2001.
- [97] Affleck G, Tennen H. Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of Personality*. 1996;64(4):899-922.
- [98] Carnelley KB, Janoff-Bulman R. Optimism about love relationships: General vs specific lessons from one's personal experiences. *Journal of Social and Personal Relationships*. 1992;9(1):5-20.
- [99] Taylor SE. Adjustment to threatening events: A theory of cognitive adaptation. *American psychologist*. 1983;38(11):1161.
- [100] Taylor SE, Brown JD. Positive illusions and well-being revisited: separating fact from fiction. 1994.
- [101] Folkman S. Revised coping theory and the process of bereavement. In: Stroebe MS, Hansson RO, Stroebe W, Schut H, editors. Handbook of bereavement research: Consequences, coping, and care. Washington, DC, US: American Psychological Association; 2001. p. 563-84.
- [102] Frankl VE. Man's search for meaning: Simon and Schuster; 1985.
- [103] Janoff-Bulman R, Berg M, Harvey J. Disillusionment and the creation of value: From traumatic losses to existential gains. *Perspectives on loss: A sourcebook*. 1998:35-47.
- [104] McIntosh DN, Silver RC, Wortman CB. Religion's role in adjustment to a negative life event: Coping with the loss of a child. *Journal of personality and social psychology*. 1993;65(4):812.
- [105] Parkes CM, Weiss RS. Recovery from bereavement: Basic Books; 1983.
- [106] Attig T. How we grieve: Relearning the world. USA: Oxford University Press; 1996.
- [107] Klass D, Silverman PR, Nickman S. Continuing bonds: New understandings of grief. USA: Taylor & Francis; 1996.
- [108] Shmotkin D. Affective bonds of adult children with living versus deceased parents. *Psychology and aging*. 1999;14(3):473.
- [109] Walter T. On Bereavement: The Culture of Grief: Open University Press; 1999.
- [110] Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *American psychologist*. 2004;59(1):20.
- [111] Bonanno GA, Papa A, O'Neill K. Loss and human resilience. *Applied and Preventive Psychology*. 2001;10(3):193-206.
- [112] Bonanno GA, Wortman CB, Lehman DR, Tweed RG, Haring M, Sonnega J, et al. Resilience to loss and chronic grief: a prospective study from preloss to 18-months postloss. *Journal of personality and social psychology*. 2002;83(5):1150.
- [113] Bonanno GA, Burton CL. Regulatory flexibility an individual differences perspective on coping and emotion regulation. *Perspectives on Psychological Science*. 2013;8(6):591-612.
- [114] Neimeyer RA. Grief counselling and therapy: the case for hope. *Bereavement Care*. 2010;29(2):13-6.
- [115] Nolen-Hoeksema S, Larson J, Larson JM. Coping with loss: Routledge; 2013.
- [116] Shear MK, Simon N, Wall M, Zisook S, Neimeyer R, Duan N, et al. Complicated grief and related bereavement issues for DSM-5. *Depression and anxiety*. 2011;28(2):103-17.
- [117] Wakefield JC. Should prolonged grief be reclassified as a mental disorder in DSM-5?: reconsidering the empirical and conceptual arguments for complicated grief disorder. *The Journal of nervous and mental disease*. 2012;200(6):499-511.
- [118] Boelen PA, Prigerson HG. Commentary on the inclusion of persistent complex bereavement-related disorder in DSM-5. *Death Studies*. 2012;36(9):771-94.
- [119] Horowitz MJ, Siegel B, Holen A, Bonanno GA, Milbrath C, Stinson CH. Diagnostic criteria for complicated grief disorder. *Focus*. 2003;1(3):290-8.
- [120] Jordan JR, Neimeyer RA. Does grief counseling work? *Death studies*. 2003;27(9):765-86.
- [121] Schut H, Stroebe MS, Van den Bout J, Terheggen M. The efficacy of bereavement interventions: Determining who benefits. 2001.
- [122] Currier JM, Holland JM, Neimeyer RA. The effectiveness of bereavement interventions with children: A meta-analytic review of controlled outcome research. *Journal of Clinical Child and Adolescent Psychology*. 2007;36(2):253-9.
- [123] Currier JM, Neimeyer RA, Berman JS. The effectiveness of psychotherapeutic interventions for bereaved persons: a comprehensive quantitative review. *Psychological bulletin*. 2008;134(5):648.
- [124] Prigerson HG, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M, Goodkin K, et al. Prolonged grief disorder:

- Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS medicine*. 2009;6(8):e1000121.
- [125] Lichtenthal WG, Cruess DG, Prigerson HG. A case for establishing complicated grief as a distinct mental disorder in DSM-V. *Clinical psychology review*. 2004;24(6):637-62.
- [126] Zhang B, El-Jawahri A, Prigerson HG. Update on bereavement research: Evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *Journal of palliative medicine*. 2006;9(5):1188-203.
- [127] Shear MK. Complicated grief. *N Engl J Med*. 2015;2015(372):153-60.
- [128] Burke LA, Neimeyer RA. Prospective risk factors for complicated grief. *Scientific foundations for health care professionals*. 2013:145.
- [129] 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):2440-51.
- [130] Bonanno GA, Westphal M, Mancini AD. Resilience to loss and potential trauma. *Annual review of clinical psychology*. 2011;7:511-35.
- [131] Massimi M, Odom W, Banks R, Kirk D, editors. *Matters of life and death: locating the end of life in lifespan-oriented HCI research*. Proceedings of the SIGCHI conference on human factors in computing systems; 2011: ACM.
- [132] Kaptelinin V, Nardi BA. *Acting with technology: Activity theory and interaction design*. MIT Press; 2006.
- [133] Lazarus RS, Folkman S. *Stress, appraisal, and coping*. Springer publishing company; 1984.
- [134] Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. *Journal of health and social behavior*. 1980:219-39.
- [135] Nolen-Hoeksema S, Larson J. *Coping with Loss*. Erlbaum; 1999.
- [136] Thoits PA. Coping, social support, and psychological outcomes: The central role of emotion. *Review of Personality & Social Psychology*. 1984;5:219-38.
- [137] Boelen PA, van den Bout J, van den Hout MA. The role of negative interpretations of grief reactions in emotional problems after bereavement. *Journal of behavior therapy and experimental psychiatry*. 2003;34(3):225-38.
- [138] Bonanno G.A., Papa A., Lalande K., Westphal M., K. C. The importance of being flexible the ability to both enhance and suppress emotional expression predicts long-term adjustment. *Psychological Science*. 2004;15(7):482-7.
- [139] Gupta S, Bonanno GA. Complicated grief and deficits in emotional expressive flexibility. *Journal of abnormal psychology*. 2011;120(3):635.
- [140] Lepore SJ, Fernandez-Berrocal P, Ragan J, Ramos N. It's not that bad: Social challenges to emotional disclosure enhance adjustment to stress. *Anxiety, Stress & Coping*. 2004;17(4):341-61.
- [141] Parkes CM. Coping with loss: Bereavement in adult life. *Bmj*. 1998;316(7134):856-9.
- [142] Leventhal H, Everhart D. Emotion, pain, and physical illness. In: Izard C, editor. *Emotions in Personality and Psychopathology*. Emotions, Personality, and Psychotherapy: Springer US; 1979. p. 261-99.
- [143] McCaul KD, Malott JM. Distraction and coping with pain. *Psychological Bulletin*. 1984;95(3):516-33.
- [144] Morris WN, Reilly NP. Toward the self-regulation of mood: Theory and research. *Motiv Emot*. 1987;11(3):215-49.
- [145] Shear K, Monk T, Houck P, Melhem N, Frank E, Reynolds C, et al. An attachment-based model of complicated grief including the role of avoidance. *European archives of psychiatry and clinical neuroscience*. 2007;257(8):453-61.
- [146] Eisma MC, Stroebe MS, Schut HA, Stroebe W, Boelen PA, van den Bout J. Avoidance processes mediate the relationship between rumination and symptoms of complicated grief and depression following loss. *Journal of Abnormal Psychology*. 2013;122(4):961.
- [147] Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychological Bulletin*. 1985;98(2):310-57.
- [148] House JS. *Work stress and social support*. Addison-Wesley Longman, Incorporated; 1981.
- [149] Schaefer C, Coyne JC, Lazarus RS. The health-related functions of social support. *J Behav Med*. 1981;4(4):381-406.
- [150] Rook KS. Research on social support, loneliness, and social isolation: Toward an integration. *Review of Personality & Social Psychology*. 1984;5:239-64.
- [151] Dimond M, Lund DA, Caserta MS. The role of social support in the first two years of bereavement in an elderly sample. *The Gerontologist*. 1987;27(5):599-604.
- [152] Stroebe W, Zech E, Stroebe MS, Abakoumkin G. Does Social Support Help in Bereavement? *Journal of Social and Clinical Psychology*. 2005;24(7):1030-50.
- [153] Walker KN, MacBride A, Vachon ML. Social support networks and the crisis of bereavement. *Social Science & Medicine* (1967). 1977;11(1):35-41.
- [154] Davis CG, Nolen-Hoeksema S. Loss and meaning: How do people make sense of loss? *American Behavioral Scientist*. 2001;44(5):726-41.
- [155] Frantz TT, Farrell MM, Trolley BC. Positive outcomes of losing a loved one. In: Neimeyer RAE, editor. *Meaning reconstruction & the experience of loss*. Washington, DC, US: American Psychological Association; 2001. p. 191-209.
- [156] Baumeister RF. The problem of life's meaning. In: Buss D, Cantor N, editors. *Personality Psychology*. Springer US; 1989. p. 138-48.
- [157] Walter T. A new model of grief: Bereavement and biography. *Mortality*. 1996;1(1):7-25.
- [158] Field NP, Gao B, Paderna L. Continuing bonds in bereavement: An attachment theory based perspective. *Death Studies*. 2005;29(4):277-99.
- [159] Lyubomirsky S, Della Porta MD. Boosting happiness, buttressing resilience. *Handbook of adult resilience*. 2010:450-64.
- [160] Lyubomirsky S, Sheldon KM, Schkade D. Pursuing happiness: The architecture of sustainable change. *Review of general psychology*. 2005;9(2):111.
- [161] Folkman S, Moskowitz JT. Coping: Pitfalls and promise. *Annu Rev Psychol*. 2004;55:745-74.
- [162] Brodsky AE, Cattaneo LB. A transconceptual model of empowerment and resilience: Divergence, convergence and interactions in kindred community concepts. *American journal of community psychology*. 2013;52(3-4):333-46.
- [163] Cattaneo LB, Goodman LA. What is empowerment anyway? A model for domestic violence practice, research, and evaluation. *Psychology of Violence*. 2015;5(1):84.
- [164] Baumeister RF. *Meanings of life*. Guilford Press; 1991.
- [165] Cantor N, Kihlstrom JF. *Personality and social intelligence*. Pearson College Division; 1987.
- [166] Cantor N, Zirkel S. *Personality, cognition, and purposive behavior*. 1990.
- [167] 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):451-82.
- [168] Bauer JJ, Bonanno GA. I can, I do, I am: The narrative differentiation of self-efficacy and other self-evaluations while adapting to bereavement. *Journal of research in personality*. 2001;35(4):424-48.
- [169] Cattaneo LB, Chapman AR. The process of empowerment: a model for use in research and practice. *American Psychologist*. 2010;65(7):646.
- [170] 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.
- [171] Vygotsky LS. *Mind in society: The development of higher psychological processes*. Harvard university press; 1980.
- [172] Leontjev AN. *Problems of the development of the mind*. 1981.
- [173] Williams A, editor. *User-centered design, activity-centered design, and goal-directed design: a review of three methods for designing web applications*. Proceedings of the 27th ACM international conference on Design of communication; 2009: ACM.
- [174] Gay G, Hembrooke H. *Activity-centered design. An Ecological Approach*. 2004.
- [175] Gifford BR, Enyedy ND, editors. *Activity centered design: Towards a theoretical framework for CSCL*. Proceedings of the 1999 conference on Computer support for collaborative learning; 1999: International Society of the Learning Sciences.
- [176] Norman DA. *The invisible computer: why good products can fail, the personal computer is so complex, and information appliances are the solution*. MIT press; 1998.
- [177] Christensen HB, Bardram JE, editors. *Supporting human activities—exploring activity-centered computing*.



- International Conference on Ubiquitous Computing; 2002: Springer.
- [178] Geyer W, Vogel J, Cheng L-T, Muller M, editors. Supporting activity-centric collaboration through peer-to-peer shared objects. Proceedings of the 2003 international ACM SIGGROUP conference on Supporting group work; 2003: ACM.
- [179] Norman DA. Human-centered design considered harmful. *interactions*. 2005;12(4):14-9.
- [180] Nardi BA. Activity theory and human-computer interaction. *Context and consciousness: Activity theory and human-computer interaction*. 1996:7-16.
- [181] Boyce C, Neale P. Conducting in-depth interviews: A guide for designing and conducting in-depth interviews for evaluation input. 2006.
- [182] Anderson C. Presenting and evaluating qualitative research. *American journal of pharmaceutical education*. 2010;74(8):141.
- [183] Charmaz K, Belgrave L. Qualitative interviewing and grounded theory analysis. *The SAGE handbook of interview research: The complexity of the craft*. 2012;2:347-65.
- [184] Leech NL, Onwuegbuzie AJ. Beyond constant comparison qualitative data analysis: Using NVivo. *School Psychology Quarterly*. 2011;26(1):70.
- [185] Welsh E, editor. Dealing with data: Using NVivo in the qualitative data analysis process. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*; 2002.
- [186] Holsti OR. Content analysis for the social sciences and humanities. 1969.
- [187] Starks H, Brown Trinidad S. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research*. 2007;17(10):1372-80.
- [188] Bottomley JS, Burke LA, Neimeyer RA. Domains of social support that predict bereavement distress following homicide loss: Assessing need and satisfaction. *OMEGA-Journal of death and dying*. 2017;75(1):3-25.
- [189] 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.
- [190] Villaceros M, Serrano I, Bermejo JC, Magaña M. Social support and psychological well-being 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.
- [191] Rothaupt JW, Becker K. A Literature Review of Western Bereavement Theory: From Decathecting to Continuing Bonds. *The Family Journal*. 2007;15(1):6-15.
- [192] Stroebe M, Schut H, Boerner K. Continuing bonds in adaptation to bereavement: Toward theoretical integration. *Clinical Psychology Review*. 2010;30(2):259-68.
- [193] Gillies J, Neimeyer RA. Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*. 2006;19(1):31-65.
- [194] Carroll E, Romano J. Your digital afterlife: When Facebook, Flickr and Twitter are your estate, what's your legacy?: New Riders; 2010.
- [195] Gulotta R, Odom W, Forlizzi J, Faste H, editors. Digital artifacts as legacy: exploring the lifespan and value of digital data. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2013: ACM.
- [196] Odom W, Sellen A, Harper R, Thereska E, editors. Lost in translation: understanding the possession of digital things in the cloud. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2012: ACM.
- [197] Massimi M, Moncur W, Odom W, Banks R, Kirk D, editors. Memento mori: technology design for the end of life. CHI'12 Extended Abstracts on Human Factors in Computing Systems; 2012: ACM.
- [198] Irandoust K, Rauterberg M, editors. How to pay attention to the end of our life: an interactive installation in cultural computing. *Culture and Computing (Culture Computing)*, 2015 International Conference on; 2015: IEEE.
- [199] Massimi M, Baecker RM. Dealing with death in design: developing systems for the bereaved. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; Vancouver, BC, Canada. 1979092: ACM; 2011. p. 1001-10.
- [200] World Internet Users Statistics and 2017 World Population Stats 2017 [Available from: <http://www.internet-worldstats.com/stats.htm>].
- [201] Odom W, Harper R, Sellen A, Kirk A, Banks R. Passing on & putting to rest: Understanding bereavement in the context of interactive technologies. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; Atlanta, Georgia, USA. 1753601: ACM; 2010. p. 1831-40.
- [202] 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):177-87.
- [203] Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L, et al. Meta-analysis: chronic disease self-management programs for older adults. *Annals of internal medicine*. 2005;143(6):427-38.
- [204] Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public health reports*. 2004;119(3):239-43.
- [205] Holmen H, Torbjørnsen A, Wahl AK, Jennum 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.
- [206] 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):439-46.
- [207] Schwarzer R. Self-efficacy: Thought control of action: Taylor & Francis; 2014.
- [208] 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):130-8.
- [209] 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.
- [210] Landro L. Doctors Prescribe New Apps to Manage Medical Conditions. *Wall Street Journal*. 2015.
- [211] 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.
- [212] 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):609-22.
- [213] Archer J. The nature of grief: The evolution and psychology of reactions to loss. New York: Routledge; 1999.
- [214] Schut H, Stroebe MS. Interventions to enhance adaptation to bereavement. *Journal of palliative medicine*. 2005;8(supplement 1):s-140-s-7.
- [215] Capps L, Bonanno GA. Narrating bereavement: Thematic and grammatical predictors of adjustment to loss. *Discourse Processes*. 2000;30(1):1-25.
- [216] 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):1117-36.
- [217] Field NP, Filanosky C. Continuing bonds, risk factors for complicated grief, and adjustment to bereavement. *Death Studies*. 2009;34(1):1-29.
- [218] 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):673-98.
- [219] 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):256-8.
- [220] 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;154:616-23.
- [221] 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.
- [222] Carr DS. Black/White differences in psychological adjustment to spousal loss among older adults. *Research on Aging*. 2004;26(6):591-622.
- [223] Houwen Kvd, Stroebe M, Stroebe W, Schut H, Bout Jvd, Meij LW-D. Risk factors for bereavement outcome: A multivariate approach. *Death Studies*. 2010;34(3):195-220.



- [224] Brown SL, Nesse RM, House JS, Utz RL. Religion and emotional compensation: Results from a prospective study of widowhood. *Personality and Social Psychology Bulletin*. 2004;30(9):1165-74.
- [225] Wijngaards-de Meij L, Stroebe M, Schut H, Stroebe W, van den Bout J, van der Heijden P, et al. Neuroticism and attachment insecurity as predictors of bereavement outcome. *Journal of Research in Personality*. 2007;41(2):498-505.
- [226] Wijngaards-de Meij L, Stroebe M, Schut H, Stroebe W, van den Bout J, van der Heijden PG, et al. Patterns of attachment and parents' adjustment to the death of their child. *Personality and Social Psychology Bulletin*. 2007;33(4):537-48.
- [227] Ericsson KA, Simon HA. Verbal reports as data. *Psychological review*. 1980;87(3):215.
- [228] Pennebaker JW, Francis ME, Booth RJ. *Linguistic inquiry and word count: LIWC 2001*. Mahway: Lawrence Erlbaum Associates. 2001;71(2001):2001.
- [229] Bird S, editor *NLTK: the natural language toolkit*. Proceedings of the COLING/ACL on Interactive presentation sessions; 2006: Association for Computational Linguistics.
- [230] Nielsen FÅ. A new ANEW: Evaluation of a word list for sentiment analysis in microblogs. *arXiv preprint arXiv:11032903*. 2011.
- [231] IBM Watson [Available from: <https://www.ibm.com/watson/alchemy-api.html>].
- [232] Kurtz ME, Kurtz J, Given CW, Given B. Predictors of postbereavement depressive symptomatology among family caregivers of cancer patients. *Supportive Care in Cancer*. 1997;5(1):53-60.
- [233] Thomas K, Hudson P, Trauer T, Remedios C, Clarke D. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a longitudinal study. *Journal of Pain and Symptom Management*. 2014;47(3):531-41.
- [234] Cleiren MP. *Bereavement and adaptation: A comparative study of the aftermath of death*: Taylor & Francis; 1993.
- [235] Laurie A, Neimeyer RA. African Americans in bereavement: Grief as a function of ethnicity. *Omega-Journal of Death and Dying*. 2008;57(2):173-93.
- [236] Roberts K, Holland J, Prigerson HG, Sweeney C, Corner G, Breitbart W, et al. Development of the Bereavement Risk Inventory and Screening Questionnaire (BRISQ): Item generation and expert panel feedback. *Palliative & supportive care*. 2017;15(1):57-66.
- [237] Feigelman W, Jordan JR, Gorman BS. How they died, time since loss, and bereavement outcomes. *OMEGA-Journal of death and dying*. 2009;58(4):251-73.
- [238] Ruggiero KJ, Del Ben K, Scotti JR, Rabalais AE. Psychometric properties of the PTSD Checklist—Civilian version. *Journal of traumatic stress*. 2003;16(5):495-502.
- [239] Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement*. 1977;1(3):385-401.
- [240] Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the connor–davidson resilience scale (CD-RISC): Validation of a 10-item measure of resilience. *Journal of traumatic stress*. 2007;20(6):1019-28.
- [241] Holland JM, Currier JM, Neimeyer RA. Validation of the integration of stressful life experiences scale—short form in a bereaved sample. *Death Studies*. 2014;38(4):234-8.
- [242] Connor KM, Davidson JR. Development of a new resilience scale: The Connor-Davidson resilience scale (CD-RISC). *Depression and anxiety*. 2003;18(2):76-82.
- [243] Campbell-Sills L, Forde DR, Stein MB. Demographic and childhood environmental predictors of resilience in a community sample. *Journal of psychiatric research*. 2009;43(12):1007-12.
- [244] Coates EE, Phares V, Dedrick RF. Psychometric properties of the Connor-Davidson Resilience Scale 10 among low-income, African American men. *Psychological assessment*. 2013;25(4):1349.
- [245] Jeste DV, Savla GN, Thompson WK, Vahia IV, Glorioso DK, Martin AvS, et al. Association between older age and more successful aging: critical role of resilience and depression. *American Journal of Psychiatry*. 2013;170(2):188-96.
- [246] Holland JM, Currier JM, Coleman RA, Neimeyer RA. The Integration of Stressful Life Experiences Scale (ISLES): Development and initial validation of a new measure. *International Journal of Stress Management*. 2010;17(4):325.
- [247] Suicide.org. suicide.org 2017 [
- [248] Curdy BH. How to link your Qualtrics survey to Amazon Mechanical Turk 2014 [Available from: <http://brentcurdy.net/qualtrics-tutorials/link/>].
- [249] Daemen J, Rijmen V. *The design of Rijndael: AES-the advanced encryption standard*: Springer Science & Business Media; 2013.
- [250] Berinsky AJ, Huber GA, Lenz GS. Evaluating online labor markets for experimental research: Amazon.com's Mechanical Turk. *Political Analysis*. 2012;20(3):351-68.
- [251] Buhrmester M, Kwang T, Gosling SD. Amazon's Mechanical Turk: A new source of inexpensive, yet high-quality, data? *Perspectives on psychological science*. 2011;6(1):3-5.
- [252] Press SJ, Wilson S. Choosing between logistic regression and discriminant analysis. *Journal of the American Statistical Association*. 1978;73(364):699-705.
- [253] Field A. *Discovering statistics using IBM SPSS statistics*: Sage; 2013.
- [254] King G, Zeng L. Logistic regression in rare events data. *Political analysis*. 2001:137-63.
- [255] Bursac Z, Gauss CH, Williams DK, Hosmer DW. Purposeful selection of variables in logistic regression. *Source code for biology and medicine*. 2008;3(1):17.
- [256] Zhang Z. Model building strategy for logistic regression: purposeful selection. *Annals of translational medicine*. 2016;4(6).
- [257] Bendal R, Afifi A. Comparison of stopping rules in forward regression. *Journal of the American Statistical Association*. 1977;72:46-53.
- [258] Mickey RM, Greenland S. The impact of confounder selection criteria on effect estimation. *American journal of epidemiology*. 1989;129(1):125-37.
- [259] Agresti A, Finlay B. *Statistical methods in social research*. San Francisco, Dellon. 1986:315-56.
- [260] Menard S. *Applied logistic regression analysis*: Sage university series on quantitative applications in the social sciences. Thousand Oaks, CA: Sage; 1995.
- [261] Liberman AM. How Much More Likely? The Implications of Odds Ratios for Probabilities. *American Journal of Evaluation*. 2005;26(2):253-66.
- [262] Baan CA, Ruige JB, Stolk RP, Witteman JC, Dekker JM, Heine RJ, et al. Performance of a predictive model to identify undiagnosed diabetes in a health care setting. *Diabetes care*. 1999;22(2):213-9.
- [263] Pearce J, Ferrier S. Evaluating the predictive performance of habitat models developed using logistic regression. *Ecological modelling*. 2000;133(3):225-45.
- [264] Anderson RP, Lew D, Peterson AT. Evaluating predictive models of species' distributions: criteria for selecting optimal models. *Ecological modelling*. 2003;162(3):211-32.
- [265] Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN. Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *The American Journal of Geriatric Psychiatry*. 2006;14(8):650-8.
- [266] Bliese PD, Wright KM, Adler AB, Cabrera O, Castro CA, Hoge CW. Validating the primary care posttraumatic stress disorder screen and the posttraumatic stress disorder checklist with soldiers returning from combat. *Journal of consulting and clinical psychology*. 2008;76(2):272.
- [267] Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin M-B. Predictors of complicated grief and depression in bereaved caregivers: a nationwide prospective cohort study. *Journal of pain and symptom management*. 2017;53(3):540-50.
- [268] Prigerson H, Ahmed I, K Silverman G, Saxena A, K Maciejewski P, Jacobs S, et al. Rates and risks of Complicated Grief among psychiatric clinic patients in Karachi, Pakistan2003. 781-92 p.
- [269] Keesee N, Currier J, Neimeyer R. Predictors of Grief Following the Death of One's Child: The Contribution of Finding Meaning2008. 1145-63 p.
- [270] Lang A. *Parental grief reactions and marital intimacy following infant death*1993.
- [271] Prigerson H, Ahmed I, Silverman GK, Saxena AK, Maciejewski PK, Jacobs SC, et al. Rates and risks of complicated grief among psychiatric clinic patients in Karachi, Pakistan. *Death Studies*. 2002;26(10):781-92.
- [272] Currier JM, Holland JM, Coleman RA, Neimeyer RA. Bereavement following violent death: An assault on life and meaning. 2008.
- [273] Callahan J. Predictors and correlates of bereavement in suicide support group participants. *Suicide and*

- Life-Threatening Behavior. 2000;30(2):104-24.
- [274] Silverman GK, Johnson JG, Prigerson HG. Preliminary explorations of the effects of prior trauma and loss on risk for psychiatric disorders in recently widowed people. *The Israel journal of psychiatry and related sciences*. 2001;38(3/4):202.
- [275] Van Doorn C, Kasl SV, Beery LC, Jacobs SC, Prigerson HG. The influence of marital quality and attachment styles on traumatic grief and depressive symptoms. *The Journal of nervous and mental disease*. 1998;186(9):566-73.
- [276] Mallinckrodt B, Wei M. Attachment, Social Competencies, Social Support, and Psychological Distress. *Journal of Counseling Psychology*. 2005;52(3):358.
- [277] Moller NP, Fouladi RT, McCarthy CJ, Hatch KD. Relationship of Attachment and Social Support to College Students' Adjustment Following a Relationship Breakup. *Journal of Counseling & Development*. 2003;81(3):354-69.
- [278] Prati G, Pietrantonio L. Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: A meta-analysis. *Journal of Loss and Trauma*. 2009;14(5):364-88.
- [279] Burke LA, Neimeyer RA, Holland JM. Inventory of Complicated Spiritual Grief: Development and Initial Validation of a New Measure. 2013.
- [280] Hogan NS, Schmidt LA. Testing the grief to personal growth model using structural equation modeling. *Death Studies*. 2002;26(8):615-34.
- [281] Feeney JA, Noller P, Hanrahan M. Assessing adult attachment. 1994.
- [282] Muris P, Mayer B, Meesters C. Self-reported attachment style, anxiety, and depression in children. *Social Behavior and Personality: an international journal*. 2000;28(2):157-62.
- [283] Gershuny BS, Sher KJ. The relation between personality and anxiety: findings from a 3-year prospective study. *Journal of abnormal psychology*. 1998;107(2):252.
- [284] Jorm AF, Christensen H, Henderson AS, Jacomb PA, Korten AE, Rodgers B. Predicting anxiety and depression from personality: Is there a synergistic effect of neuroticism and extraversion? *Journal of abnormal psychology*. 2000;109(1):145.
- [285] Kendler KS, Kuhn J, Prescott CA. The interrelationship of neuroticism, sex, and stressful life events in the prediction of episodes of major depression. *American Journal of Psychiatry*. 2004;161(4):631-6.
- [286] Breslau N, Schultz L. Neuroticism and post-traumatic stress disorder: a prospective investigation. *Psychological medicine*. 2013;43(8):1697-702.
- [287] van den Hout MA, Engelhard IM. Pretrauma neuroticism, negative appraisals of intrusions, and severity of PTSD symptoms. *Journal of Psychopathology and Behavioral Assessment*. 2004;26(3):181-3.
- [288] Hauser DJ, Schwarz N. Attentive Turkers: MTurk participants perform better on online attention checks than do subject pool participants. *Behavior research methods*. 2016;48(1):400-7.
- [289] Miyajima K, Fujisawa D, Yoshimura K, Ito M, Nakajima S, Shirahase J, et al. Association between quality of end-of-life care and possible complicated grief among bereaved family members. *Journal of palliative medicine*. 2014;17(9):1025-31.
- [290] Peng C-YJ, Lee KL, Ingersoll GM. An introduction to logistic regression analysis and reporting. *The journal of educational research*. 2002;96(1):3-14.
- [291] Allen JY, Haley WE, Small BJ, Schonwetter RS, McMillan SC. Bereavement among hospice caregivers of cancer patients one year following loss: predictors of grief, complicated grief, and symptoms of depression. *Journal of palliative medicine*. 2013;16(7):745-51.
- [292] BrintzenhofeSzoc KM, Smith ED, Zabora JR. Screening to predict complicated grief in spouses of cancer patients. *Cancer practice*. 1999;7(5):233-9.
- [293] Meert KL, Donaldson AE, Newth CJ, Harrison R, Berger J, Zimmerman J, et al. Complicated grief and associated risk factors among parents following a child's death in the pediatric intensive care unit. *Archives of pediatrics & adolescent medicine*. 2010;164(11):1045-51.
- [294] Nanni MG, Biancosino B, Grassi L. Pre-loss symptoms related to risk of complicated grief in caregivers of terminally ill cancer patients. *Journal of affective disorders*. 2014;160:87-91.
- [295] Strobe W, Schut H, Stroebe M, Hanson R, Stroeve W, Schut H. Risk factors in bereavement outcome: A methodological and empirical review. *Handbook of Bereavement Research Consequences, Coping and Care* Washington, DC: American Psychological Association. 2001:349-71.
- [296] Bonanno GA, Field NP. Examining the delayed grief hypothesis across 5 years of bereavement. *American Behavioral Scientist*. 2001;44(5):798-816.
- [297] Finkel S, Czaja SJ, Martinovich Z, Harris C, Pezzuto D, Schulz R. E-care: a telecommunications technology intervention for family caregivers of dementia patients. *The American journal of geriatric psychiatry*. 2007;15(5):443-8.
- [298] Timmermans S, Berg M. The practice of medical technology. *Sociology of health & illness*. 2003;25(3):97-114.
- [299] Lawton J. *The dying process: patients' experiences of palliative care*: Routledge; 2002.
- [300] Aujoulat I, Marcolongo R, Bonadiman L, Deccache A. Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social science & medicine*. 2008;66(5):1228-39.
- [301] Pellino T, Tluczek A, Collins M, Trimbom S. Increasing self-efficacy through empowerment: preoperative education for orthopaedic patients. *Orthopaedic Nursing*. 1998;17(4):48.
- [302] Vauth R, Kleim B, Wirtz M, Corrigan PW. Self-efficacy and empowerment as outcomes of self-stigmatizing and coping in schizophrenia. *Psychiatry research*. 2007;150(1):71-80.
- [303] Zimmerman BJ, Bonner S, Kovach R. Developing self-regulated learners: Beyond achievement to self-efficacy: American Psychological Association; 1996.
- [304] Barelo S, Graffigna G, Vegni E. Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nursing research and practice*. 2012;2012.
- [305] Morden A, Jinks C, Ong BN. Rethinking 'risk' and self-management for chronic illness. *Social Theory & Health*. 2012;10(1):78-99.
- [306] Swan M. Health 2050: the realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of personalized medicine*. 2012;2(3):93-118.
- [307] Ybarra ML, Eaton WW. Internet-based mental health interventions. *Mental health services research*. 2005;7(2):75-87.
- [308] Lupton D. The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*. 2013;11(3):256-70.
- [309] Berinsky AJ, Margolis MF, Sances MW. Separating the shirkers from the workers? Making sure respondents pay attention on self-administered surveys. *American Journal of Political Science*. 2014;58(3):739-53.
- [310] Buhrmester M. M-Turk Guide 2017 [Available from: <https://michaelbuhrmester.wordpress.com/mechanical-turk-guide/>].
- [311] Oppenheimer DM, Meyvis T, Davidenko N. Instructional manipulation checks: Detecting satisficing to increase statistical power. *Journal of Experimental Social Psychology*. 2009;45(4):867-72.
- [312] Vannette D. Using Attention Checks in Your Surveys May Harm Data Quality 2017 [Available from: <https://www.qualtrics.com/blog/using-attention-checks-in-your-surveys-may-harm-data-quality/>].

## Curriculum Vitae

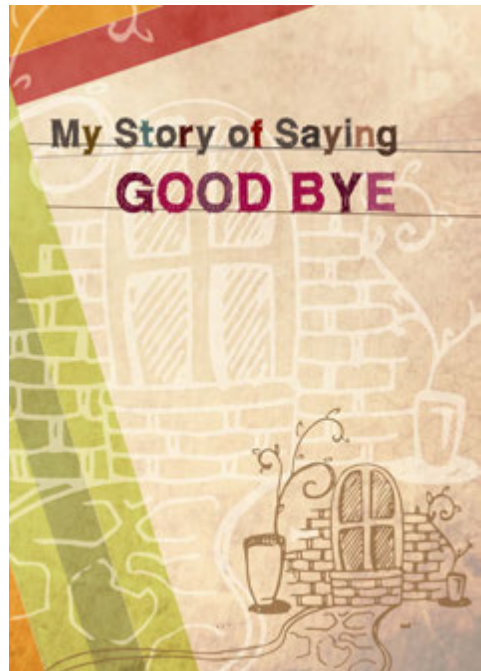
Wan Jou She was born on 19-09-1987 in Kaohsiung City, Taiwan.

After finishing the bachelor degree in 2009 at National ChengChi University in Taipei, Taiwan, she studied Creative Industries Design at National Cheng Kung University in Tainan City, Taiwan. In 2012 she graduated within the Marketing and Branding Research Group on Service Design for Potential Breakup Market. From 2012 to 2015 she started a PhD project at the Delft University of Technology at Delft, the Netherlands, and from 2015 to 2018 at the Eindhoven University of Technology at Eindhoven, the Netherlands of which the results are presented in this dissertation. Since 2015 she is employed at the Eindhoven University of Technology.

# Appendices

## Appendix 1. Sensitizing booklets

### Assignment book for 6 days







## SOMETHING ABOUT MYSELF



Name:

Gender:

Age:

Ethnicity:

Educational level:

Religion:

Cultural background:

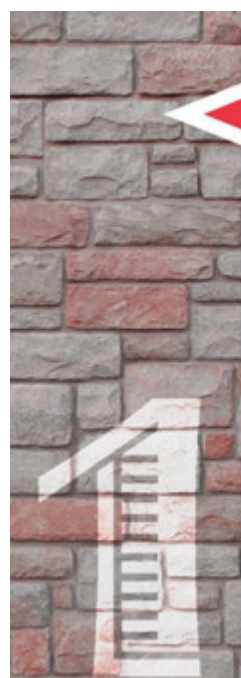
Occupation:



## THE LIFE STORIES BETWEEN US



- ★ Our favorite activities when being together...
- ★ The most unforgettable memory between us
- ★ The best gift from him/her is...



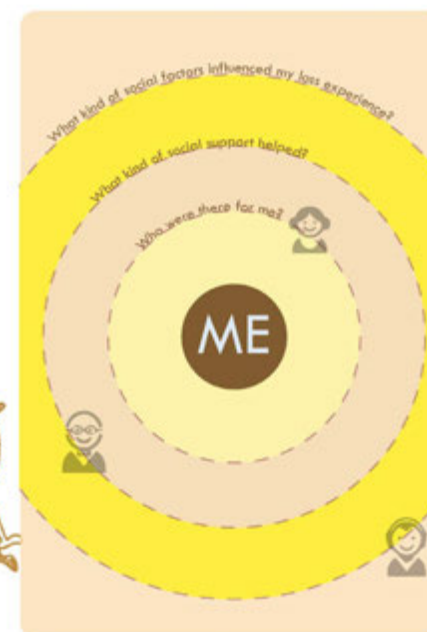
## MY RELATIONSHIP WITH



- ★ My loss experience is about my relationship with...  
(your friend, partner, family member or pet...etc)
- ★ How did this figure play a role in my past relationship?
- ★ We separated because...
- ★ How does this figure play a role in my current life?



## SOCIAL CONTEXT IN LOSS







## THE SYMBOLIC THINGS



★ I think \_\_\_\_\_ symbolizes my lost relationship

Provide pictures, sketches or digital files

★ The story behind it is.....



## THE GIFT FROM LOSS



★ After losing him/her, I created...  
(notes, poems, articles, songs, photos, drawings...etc)

★ By creating these, I tried to



2

My daily life looks like this

3

The funniest photo about him/her  
The occasion is...

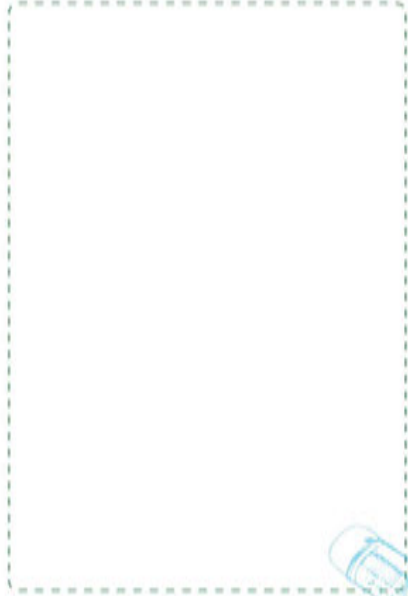


6



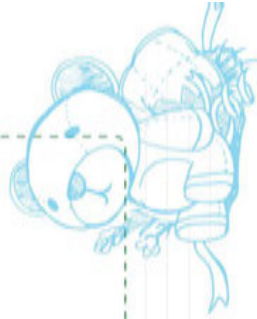
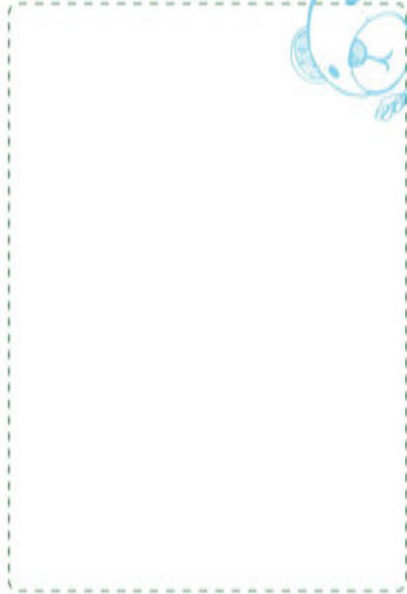
How we interact

4



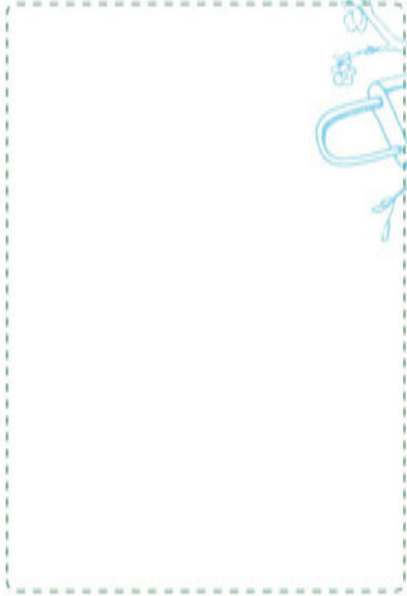
My best time with him/her  
The occasion is

7



The gift from him/her  
The occasion is

5



This photo makes me miss him/her most  
Because

10



Photos from work / home / etc...

8

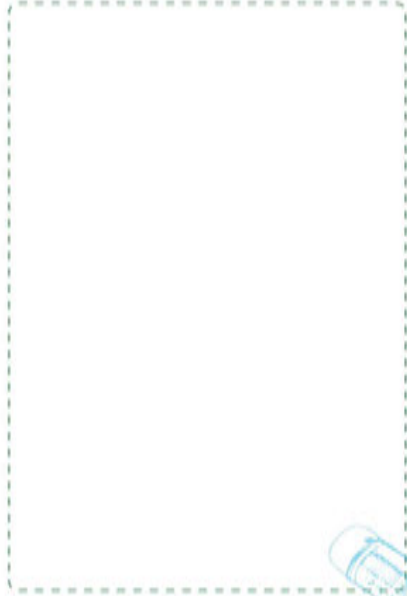
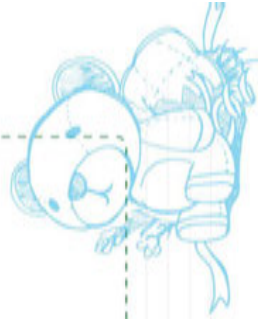
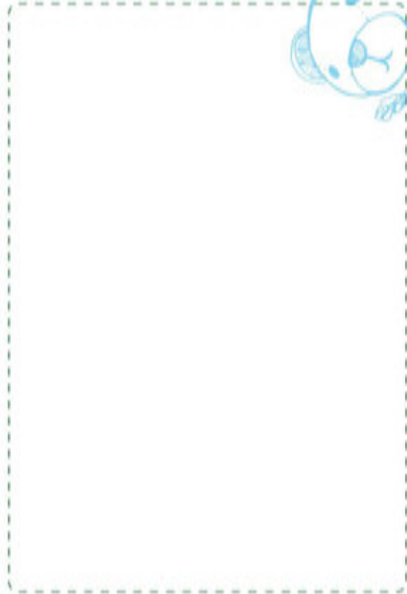


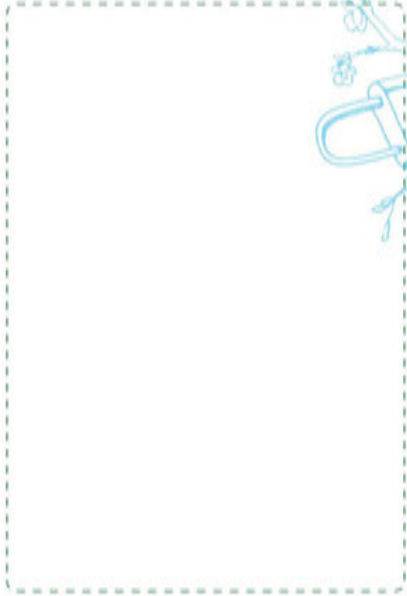
Photo which was secretly taken without his/her notice

11



Other interesting photos

9



My current life with other important figures

## Appendix 2. Study Questions for Protocol Analysis

### GIFT Protocol Analysis Script

(To be conducted following completion of GIFT;  
directions are in italics; questions are numbered)

*“Thank you for agreeing to participate in this study and brief interview. The purpose of this research is to get your feedback on the perceived usefulness and difficulties of using the GIFT app, in general, and the comprehensibility and relevance of the grief self-monitoring statements. Your input will contribute to making this app more user-friendly and meaningful to future users. I will audio-tape your responses. First, though, it is important that I set a few guiding principles. For instance, in offering your feedback to specific questions, I want you to know that there are **no wrong answers or comments**. And, because I am very interested in protecting your privacy, these sessions are kept **confidential**—everything we share here stays here and is not to be shared outside of this room. This idea of confidentiality extends to me, the researcher, as well. I will not use your real name in my notes, transcriptions of the audio recording, or anything that stems from this session. Are there any questions about any of those things?*

1. OK, before starting, I would like to understand if you have had other experiences of seeking support or searching for grief related information on the Internet?

If yes:

- would you mind sharing a bit of your experiences on using the Internet to understand your grief or to seek for support?
- What kind of information or websites did you consider helpful?

If no:

Do you have a specific reason that you didn't turn to the Internet for support in the past?

[Transition Statement]

*Now, I'd like your comments on topics specifically related to our study. For instance: I'd like to have you look back at three of the questionnaires that you filled out when completing GIFT: **the Background Information, the CGRF, and the BRISQ questionnaire**. These questionnaires asked you to tell us a little about yourself and also to respond to a number of items related to your loss experience. We want you to help us evaluate these questionnaires because we want to know how to improve them to ensure that they ask meaningful questions of bereaved individuals. For example:*

2. Which item(s) were hard to understand? (i.e., confusing or difficult wording, unsure what was being asked)
3. Which questionnaire(s) did you think were particularly relevant to you? (i.e., on target, meaningful, relevant to cultural background)
4. Which questionnaire(s) do you think might be particularly relevant to other grievers?
5. Which questionnaire(s) would you say were least relevant to you?
6. Which questionnaire(s) would you say might be least relevant to other grievers?
7. What do you feel are the potential benefits of using GIFT?

8. What, if anything, was challenging for you in using GIFT?

9. To what extent do you think the questionnaire result(s) delivered by GIFT were trustworthy?  
REPEAT questions 2-5 in relation to the feedback the participant received from the GIFT app.

[Final Questions]

*We have a few final questions for you. First:*

10. What have we missed?

11. Is there anything that you didn't get a chance to say?

12. And, finally, what is one word or short phrase you would use to describe your experiences of using GIFT?

Great! Your help with this is invaluable to me, and I really appreciate the extra time and effort you put toward helping us in this way.”

Appendix 3. Questionnaires for GIFT study: Background information

1. Information about me:  
My gender: a) Male b) Female c) Other
2. My age: year of birth (the system calculates the age automatically)
3. I am my deceased loved one's (check one) :
4. My nationality (e.g., American, Italian, Australian) \_\_\_\_\_
  - a. spouse
  - b. partner/fiancé
  - c. boyfriend
  - d. girlfriend
  - e. daughter
  - f. son
  - g. mother
  - h. father
  - i. grandmother
  - j. grandfather
  - k. grandson
  - l. granddaughter
  - m. aunt
  - n. uncle
  - o. stepmother
  - p. stepfather
  - q. sister
  - r. brother
  - s. cousin
  - t. sister-in-law
  - u. brother-in-law
  - v. friend
  - w. coworker
  - x. other
5. My country of residence (e.g., New Zealand, USA, Argentina) \_\_\_\_\_
6. My marital status is: (choose one)
  - a. Single, not in a committed relationship
  - b. Married, or in a committed relationship
  - c. Separated
  - d. Divorced
  - e. Widowed
7. My years of formal schooling, from early childhood to present:
  - a. 0-8 years
  - b. 9-12 years
  - c. 13-14 years

- d. 15-16 years
- e. 17- 20 years
- f. More than 20 years
8. My employment status? (choose one)
  - a. Employed full-time (greater than 30 hours per week)
  - b. Employed part-time (less than 30 hours per week)
  - c. Not currently employed, looking for work
  - d. Not currently employed, not looking for work
  - e. Full time student
  - f. Other, please explain \_\_\_\_\_
9. The faith tradition with which I **most closely** affiliate (e.g., Buddhism, Judaism, Christianity, Islam, Secular/Nonreligious/Agnostic) \_\_\_\_\_
10. On average, I engage in **personal or public** religious activities pertaining to my faith/spirituality... (e.g., personal prayer or reading of sacred text, attend synagogue meeting, religious festivals, Bible study group, spiritual retreat) (Choose one)
  - a. Never
  - b. Once per year
  - c. At least twice per year
  - d. At least once per month
  - e. At least twice per month
  - f. At least once per week
  - g. At least twice per week
  - h. Daily
11. I consider faith / spirituality...
  - a. Totally irrelevant
  - b. Somewhat important
  - c. Not very important
  - d. Very important
  - e. Extremely important



12. Other than the deceased loved one I am currently grieving, in the past 3 years, I have also experienced the death of \_\_\_\_ loved ones (family members or close friends).
13. Other than the deceased loved one I am currently grieving, my most recent loss of a family member or a close friend to death was approximately \_\_\_\_years **or** \_\_\_\_ months ago.

Information about my deceased loved one (please focus on only **one** loss for this study):

1. My loved one's **first** name: \_\_\_\_\_(use first name only)
2. His or her gender: a) female b) male c) other
3. My loved one died \_\_\_\_years or, if less than one year, \_\_\_\_months ago.
4. My loved one's age at the time of his/her death was\_\_\_\_years or, if less than one year, \_\_\_\_months old.
5. My loved one died of :
  - a. Natural anticipated death (e.g., old age, terminal illness)
  - b. Natural sudden death (e.g. heart attack, unexplained illness)
  - c. Homicide
  - d. Suicide
  - e. Fatal accident (e.g., motor vehicle accident, drowning, electrocution, fall)
  - f. Medical malpractice (e.g., wrongful death following birthing, surgery, or other procedure)
  - g. Terrorism
  - h. Natural disaster (e.g., earthquake, hurricane)
  - i. Other (please explain \_\_\_\_\_)
6. Before my loved one died, I knew him/her for \_\_\_\_years **or**, if less than one year, \_\_\_\_months.
7. Before my loved one died, I was in contact with him/her (choose one):
  - a. 2-7 times per week
  - b. once per week

- c. every other week
- d. once per month
- e. less often than once per month

Appendix 4. Questionnaires for GIFT study: Risk Factor Questionnaire

For each of the following items, please answer Yes or No to indicate whether it is more true or not true for you.

A. Personal Factors \* reverse score to capture RF

1. I consider myself a rather nervous person.
2. I struggled with mental health problems even before the loss (e.g., depression, anxiety).
3. I believe that professional counseling or grief therapy could help me with my loss.
4. I'm troubled by my own reactions to this loss.
5. Religion/faith/spirituality plays a major role in my life. \*
6. I have philosophical beliefs that I rely on to deal with this loss. \*
7. My limited income is a source of stress for me.

B. Relationship to the Deceased

1. I felt emotionally close to my loved one. \*
2. I relied heavily on my loved one when he/she was alive.
3. When my loved one was alive there was often conflict between us.
4. I have regrets about my relationship with my loved one that I cannot now resolve.
5. I often felt emotionally and physically overwhelmed by caregiving for my loved one before the death.

C. Relationship to Others

1. I have no one I can talk to openly and honestly about my grief.
2. I feel uncomfortable letting people get close to me emotionally.
3. Most of my family seems distant, unsupportive, or disconnected in relation to my loss.
4. I use technology to stay connected with people (Facebook, email, texts, phone). \*
5. Friends or family members are frequently concerned about how I am grieving.

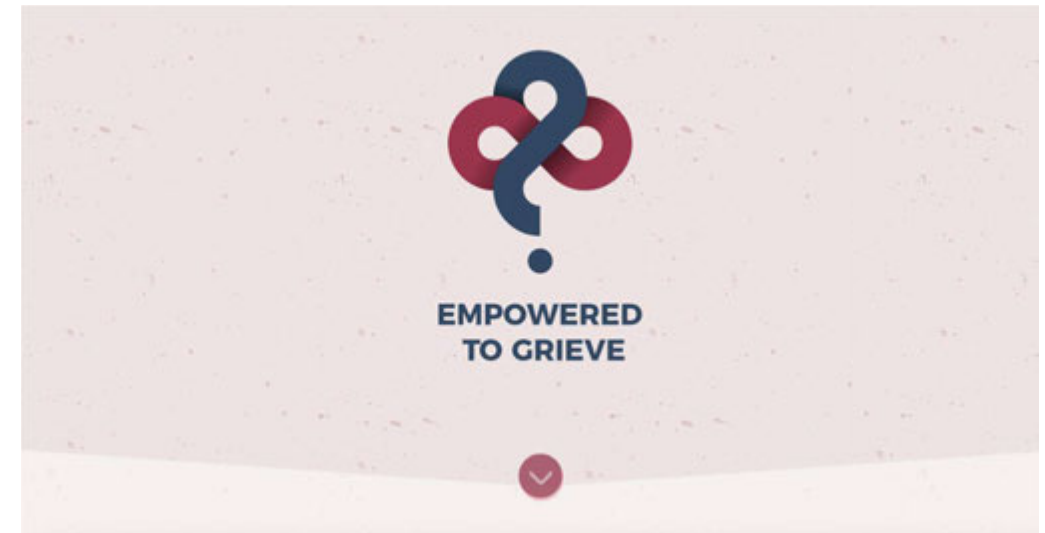
D. Death-Related Factors

1. My loved one died suddenly and without warning.
2. I believe that my loved one's death was preventable.

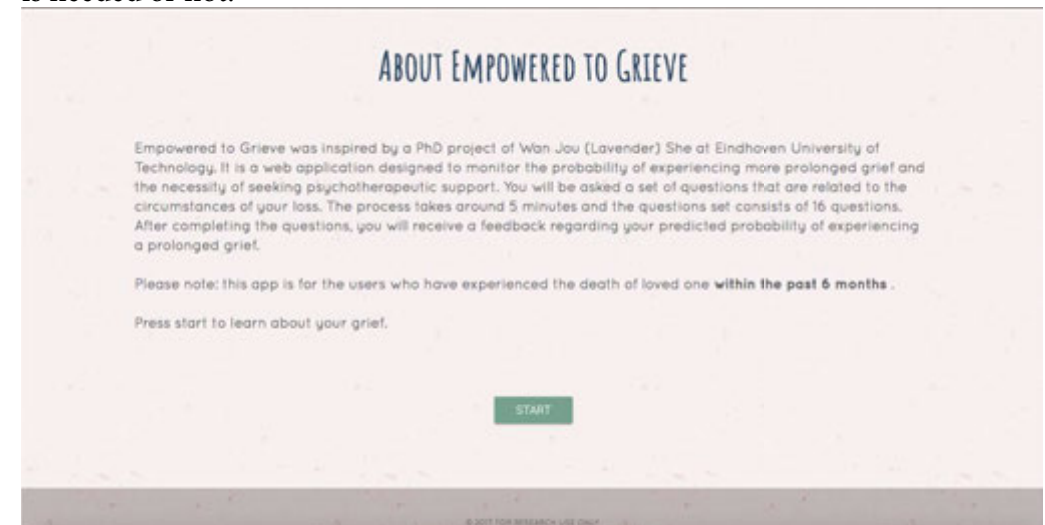


3. I feel overwhelmed by the number of losses of significant people that I have experienced recently.
4. I have struggled to make sense of the loss, or to find any meaning in it.
5. My loved one might have lingered for too long before the death.
6. I worry that my loved one suffered while dying.
7. I was unprepared for my loved one to die.
8. I continue to be troubled by images of my loved one's dead body and/or the death scene.

#### Appendix 5. Introduction to Empowered to Grieve (EtG)



Empowered to Grieve is the deliverable of this thesis. It is targeting on the bereaved internet users who have experienced death of a loved one within six months. Users are expected to answer a set of questions related to their loss circumstances and receive the feedback regarding whether a clinical intervention is needed or not.



The introduction page would specify the types of users the app would benefit. This app does not require login. Users would simply click on start and enter their information.

1 of 16: Your gender is...

☐ Male ☒ Female ☐ Other

2 of 16: Your year of birth is...

Select your birth year...

3 of 16: You are the lost person's...

<input type="radio"/> spouse	<input type="radio"/> partner/fiancé	<input type="radio"/> boyfriend
<input type="radio"/> girlfriend	<input type="radio"/> daughter	<input type="radio"/> son
<input type="radio"/> mother	<input checked="" type="radio"/> father	<input type="radio"/> grandmother
<input type="radio"/> grandfather	<input type="radio"/> grandson	<input type="radio"/> granddaughter
<input type="radio"/> aunt	<input type="radio"/> uncle	<input type="radio"/> stepmother
<input type="radio"/> stepfather	<input type="radio"/> sister	<input type="radio"/> brother
<input type="radio"/> cousin	<input type="radio"/> sister-in-law	<input type="radio"/> brother-in-law
<input type="radio"/> friend	<input type="radio"/> co-worker	
<input type="radio"/> Other	Please describe	

The input layout of the questions is similar to GIFT, and we implemented the Material Design style from Google Design.

4 of 16: Your employment status is...

☐ Employed full-time (greater than 30 hours per week)

☐ Employed part-time (less than 30 hours per week)

☒ Not currently employed, looking for work

☐ Not currently employed, not looking for work

☐ Full time student

☐ Other Please describe

5 of 16: The lost person died of...

☐ Natural anticipated death (e.g., old age, terminal illness)

☐ Natural sudden death (e.g., heart attack, unexplained illness)

☐ Homicide

every other week

once per month

☒ less often than once per month

7 of 16: To what extent have you had periods of depression, anxiety or other emotional or mental health concerns in your life?

Not at all A little Somewhat Quite a bit A great deal

The questionnaire will automatically scroll down to the next question. Since all 16 questions need to be answered to yield a prediction result, users are only navigated to the next question after the previous one is answered (e.g., the above figure shows that question 7 is the last question, but after user answers question 7, question 8 will be appended below).

8 of 16: To what extent have you experienced challenges (for example, loss, separation, abuse) that were traumatic for you?

Not at all A little Somewhat Quite a bit A great deal

9 of 16: Are you upset about how the lost person died? Rather than the cause of death, by this we mean the circumstances surrounding the lost person's death such as uncontrolled pain, difficulty breathing, delirium, or being alone.

Not at all Slightly Somewhat Very Extremely

10 of 16: Are you feeling angry about any aspect of the lost person's illness experience, medical treatment or death?

Not at all   Slightly   Somewhat   **Very**   Extremely

11 of 16: How often do you find that you feel empty or emotionally numb since the death of the lost person?

Never   Rarely   **Occasionally**   A moderate amount   A great deal

13 of 16: Do you feel like you are struggling with your sense of identity since the lost person's death?

Not at all   Slightly   Somewhat   Quite a bit   **Very much**

14 of 16: You consider faith / spirituality...

Totally irrelevant   **Not very important**   Somewhat important   Very important   Extremely important

In the last question, users could view the result based on the answer they have provided. The feedback will be displayed and the probability of predicted outcome will be animated above the feedback.

15 of 16: Your limited income is a source of stress for you.

Strongly disagree   Disagree   **Neither agree nor disagree**   Agree   Strongly agree

16 of 16: You continue to be troubled by images of the lost person's dead body and/or the death scene.

Strongly disagree   Disagree   **Neither agree nor disagree**   Agree   Strongly agree

[VIEW RESULT](#)

**3%**

**FEEDBACK**

Your predicted probability of experiencing a protracted and intense grief is 3%. A probability lower than 50% does not place you in the range of people who are likely to develop prolonged or complicated grief. It does not suggest that coping with bereavement would be necessarily easier for you, but your result suggests that you exhibit good potential to adapt to the loss. The feedback from previous questions does not intend to diagnose you; rather, it should be considered a chance to revisit your ways of coping with bereavement. If you still feel the necessity to seek professional support, it is suggestive to contact a grief counselor or a therapist who specializes in bereavement care.



The final outcome can be downloaded as a jpg file.

