

**Acceptability and feasibility of an ESM-study examining grief in
daily life of bereaved people**

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Abstract

Introduction

While research on a Prolonged Grief Disorder (PGD) is increasing, less is known about the day-to-day grief experiences of people who have PGD. This study converted items of the Traumatic Grief Inventory Self-Report Plus (TGI-SR+) to make them suitable for Experience Sampling Method (ESM) -research. This conversion was done with the help of experts on ESM and/or PGD. Thereafter, this study aimed to evaluate the feasibility and acceptability of conducting daily measurements of grief reactions in bereaved people. Feasibility was evaluated by examining compliance- and retention rates. Acceptability was evaluated by comparing the results on reformulated items from the Reactions to Research Participation Questionnaire (RRPQ), with the results of a similar study.

Method

Experts were asked to assist in the conversion of items of the TGI-SR+ to make them suitable for ESM-research. This was done with a Three-Step Test-Interview (TSTI). These converted items were then implemented in a smartphone-assisted ESM study over a two-week period with 5 measurements a day. Eighty bereaved people from the Netherlands or Germany joined the study and were interviewed before and after the ESM-period to examine possible effects of the study. The interviews consisted of questionnaires such as the Patient Health Questionnaire (PHQ) and the last interview also included reformulated items of RRPQ. The median and range of the TSTI was calculated to evaluate the suitability of converted items. Compliance and retention rates were examined by calculating the percentage of completed surveys. Results of the adapted items from the RRPQ were compared with the results from a similar ESM-study by conducting an independent sample t-test.

Results

The converted items were deemed suitable for ESM implementation based on expert reviews. Compliance- and retention rates were relatively low compared with other ESM studies. There were no significant associations found regarding characteristics (e.g. gender, age) and participants who were either considered as dropouts or completers. Bereaved people in this study indicated less personal benefits and emotional reactions regarding the ESM-period, compared with a similar study. These findings were not significant.

Discussion

The converted ESM items might be used in future ESM-research. However, we did not examine the fluctuation of the PGD symptoms. This should be subject of future research. Feasibility might be increased by implementation of aspects such as higher incentives and less measurements per day. Moreover, a heterogeneous sample consisting of people with and without PGD, might prove beneficial for research purposes and increase the compliance- and retention rates. Finally, this study showed that ESM studies on grief are in all probability acceptable regarding personal benefits and emotional reactions.

Introduction

When a loved one dies, this can have a major negative influence on the lives of those left behind. For some people this can cause serious disruption of their functioning in daily life for a longer period of time. One out of ten people have difficulty to adapt to a life without their loved one after bereavement (Lundorff et al., 2017). For a prolonged period of time, they experience elevated grief reactions, such as preoccupation with their deceased loved one.

According to the text revision of the fifth edition of the classification system of the Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM-5-TR) this can lead to a *Prolonged Grief Disorder* (PGD) (American Psychiatric Association, 2022). People with this disorder experience multiple symptoms, such as identity disruption and intense loneliness as a consequence of the death of a loved one that occurred at least 12 months ago.

PGD is frequently comorbid with depression, post-traumatic stress disorder (PTSD), other anxiety disorders and suicidal ideation (Heeke et al., 2019). Although these disorders are comorbid and quite similar, studies do show that symptoms of PGD differ from depressive symptoms and post-traumatic symptoms (Boelen & van den Bout, 2005; Prigerson et al., 1996). Multiple researches have been conducted on well-known disorders such as depression and PTSD. Among those researches, there are studies that examine depression and PTSD in daily life, which is important for possible implementations in clinical practice and therapeutic interventions. For instance, Minaeva et al. (2020) showed that daily measurements are a good diagnostic predictor for depression. Alting van Geusau et al. (2021) investigated factors that could predict treatment outcomes for PTSD. Researches that include daily measures regarding grief are lacking. Studying grief in daily life might be relevant because it may shed light on fluctuations of grief symptoms and provide insight for future therapies and interventions

A way of measuring day-to-day fluctuations is by using Experience Sampling methodology (ESM). It was developed to investigate subjective experience over time and

across naturally occurring situations (Csikszentmihalyi & Larson, 2014). ESM is a research methodology to measure what people are feeling, doing and thinking in their daily lives. It asks individuals to provide multiple self-assessments per day at random or fixed moments during a week.

Since there are no ESM-studies on grief, it is unknown whether it is feasible and acceptable to conduct an ESM study including bereaved people. In order to study grief in daily life, items to assess grief need to be developed. One way to develop ESM-items is to use an existing validated questionnaire or measure to assess symptoms retrospectively and convert those items for daily measurement. For instance, Kleim et al. (2013) used the Clinician Administered PTSD scale (CAPS) as guideline. They then transformed the items to make it suitable for ESM, by asking the participants their three most frequent index trauma intrusions 10 times in 7 days. This concerns the trigger, content, intrusion characteristics, emotional response and cognitive-behavioral response.

One challenge regarding the feasibility of ESM-studies is participant attrition (Waterman et al., 2019). ESM-studies present increased participant burden because they involve many data collection points, which may cause participants to leave the studies. Feasibility of a study is related to the compliance- and retention rates (Vachon et al., 2019). The compliance rate can be defined as the ratio of the number of self-evaluations that participants actually completed over the theoretical maximum number of self-evaluations allowed by the protocol (0%-100% when expressed as a percentage), whereas the retention rate refers to the proportion (or percentage) of participants included in the final analyses. Feasibility of a study can be evaluated by examining the compliance- and retention rate and compare them with prior ESM-research.

Another important issue regarding the acceptability of the application of ESM to loaded topics such as intimate partner violence (IPV) and grief, is research reactions.

Participants may have negative or positive feelings toward the survey, including aspects such as emotional reactions and perceptions of personal benefits (Waterman et al., 2019).

Waterman et al. (2019) stated that multiple researches on IPV showed that it is well-tolerated by participants. Many participants even reported personal benefits to research participation, such as validation and opportunity to gain self-knowledge (Edwards et al., 2017). Sullivan et al. (2011) assessed participant's reactions to participating in an ESM of IPV. Although 72% reported that they did not find it difficult to share their IPV experiences, this means that 28% does find it difficult. It is therefore important to evaluate the acceptability of the study. A way to evaluate the acceptability of this study is by using items similar to previous research and compare the results. In this study, the research of Waterman et al. (2019) about IPV will be used as comparison. They showed that overall negative reactions were infrequently endorsed and when they were felt, perceived to not be long-lasting. Waterman et al. (2019) used items from the Reactions to Research Participation Questionnaire (RRPQ) (Newman & Kaloupek, 2004) and reformulated them to make them suitable for daily diary measures.

The evaluation of converted items to ESM, the feasibility of ESM study regarding participants with grief and its acceptability, result in the following explorative research questions:

- 1) Based on expert interviews, is it suitable to examine PGD symptoms in daily life of bereaved people?
- 2) To what extent is performing an ESM study on grief feasible in terms of the compliance- and retention rates in bereaved people, looking at the characteristics of dropouts and completers?
- 3) To what extent is performing an ESM study on grief acceptable in terms of the possible cognitive- and emotional burden according to bereaved people who participated in an ESM-study?

Methods

Participants for expert review on suitability of ESM items

To be able to give an answer on whether the items are suitable for ESM, experts on ESM-research and/or PGD researchers and/or practitioners who worked with relatives with PGD could participate in this research. These experts were contacted via the social network of the research team with emails. Their data was collected in the period of October 2021 to December 2021.

Participants for ESM study on grief in bereaved people

To be included in the research, participants needed to be 18 years or older who lost a significant other at least three months earlier. Moreover, they needed to be able to speak Dutch or German, own a smartphone, not have been diagnosed with a psychotic disorder and not be highly suicidal. The bereaved people were recruited via social media and mouth-to-mouth promotion of the study.

In the ESM review of Vachon et al. (2019) the majority of studies have a sample size between 50 to 99 participants. In the study of Gabriel et al. (2018) they state that the mean sample size was 83 (SD = 32). The goal of this study regarding sample size was gaining a sample between those numbers.

Design and Procedure

Before the start of the study, an ethical approval (request number: 211167) was granted by the BMS ethical committee of the University of Twente.

Design and procedure regarding the experts

Subsequently, an information letter was first sent to experts on ESM and/or PGD.

They could join to facilitate in the conversion of items of the Traumatic Grief Inventory Self-Report Plus (TGI-SR+) (Lenferink, Eisma, Smid, Keijser & Boelen, 2022). After they gave their consent, their feedback was gathered and implemented by using the Three-Step Test-Interview (TSTI) (for more information see Paragraph “TSTI with experts”). These interviews were conducted online and took approximately 20 to 30 minutes.

Design and procedure regarding the bereaved people

Then bereaved people were invited to join the study. One of the bereaved people could win a gift card of 50 euros from bol.com as an incentive. In case they read all the information and would like to join, they needed to fill in a statement of consent. Within a few weeks they were called to schedule an interview via telephone. This interview took place preferably the day before the start of the ESM research period (bereaved people were asked to begin the app-phase on the day after the interview, but could start when they wanted). This was a 30-minute telephonic interview. It consisted of two parts. The first part had questions about the background of the participant, the background of the deceased person and questions about possible psychological help the participant received, linked to the bereavement. The second part included possible emotional reactions a participant might have had. Thereafter, the participants received an email in which information was provided on how to download, install and use the app. The app was programmed to emit five signals each day for completing a short survey. Every three hours, starting from 8:30h, they received a survey consisting of 11 items of PGD symptoms and contextual items. If participants missed the signal, they received a reminder after 10 and 20 minutes. Delespaul (1995) showed that reports are less valid and reliable if they are finished after the interval of 15 minutes after a signal. However, due to participants having work or other responsibilities, they were able to finish surveys within 60 minutes after the signal. In that manner, the chance of participants not filling in all surveys

was reduced. The participants received the daily notifications for 14 consecutive days. All the items that measured PGD symptoms had answering options on a 6-point Likert scale (0 = Not at all, 6 = Very much). A second telephone interview was scheduled within three days after the end of the ESM-phase. This second interview was similar to the first interview, but also contained questions on how the bereaved people experienced the two-week ESM period.

TSTI with experts

Other studies that did research on depressive symptoms (Ben-Zeev & Young, 2010; Dejonckheere, Bastian, Fried, Murphy & Kuppens, 2017) and Posttraumatic Stress Disorder (PTSD) (Pfaltz, Michael, Meyer & Wilhelm, 2013) in daily life were reviewed, to see how other studies converted existing questionnaires into items suitable for ESM. The ESM-items for this study are based on the items of the TGI-SR+ (Lenferink, Eisma, Smid, Keijser & Boelen, 2022). They concluded that the TGI-SR+ is a reliable and valid measure to assess symptoms of PGD according to the DSM-5-TR. Where items of the TGI-SR+ concern symptoms of PGD in the last month, this study converted those items in order to measure PGD symptoms in the last three hours. The Three-Step Test-Interview (TSTI) (Hak, van der Veer & Jansen, 2008) is a method for pretesting a self-completion questionnaire by first observing actual instances of interaction between the instrument and respondents (the response process) before exploring the reasons for this behavior. It consists of the following three steps: observation of response behavior, follow-up probing aimed at remedying gaps in observational data and debriefing aimed at eliciting experiences and opinions (Hak, van der Veer & Jansen, 2008).

Measures

This study included two interviews that consisted of questionnaires such as the Patient Health Questionnaire-9 (PHQ-9). In this manner it was possible to examine the extent of symptomatology of bereaved people (e.g. depressive symptoms) before and after the study period.

Reactions to Research Participation Questionnaire

The Reactions to Research Participation Questionnaire (RRPQ) (Newman & Kaloupek, 2004) was used to evaluate the acceptability of this study. The original questionnaire is a 23-item scale designed to assess participant's reactions to research participation, which is scored using five subscales (Participation, Personal Benefit, Global Evaluation, Drawbacks, and Emotional Reactions), each of which is scored using a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). However, given that this five-factor structure has not been replicated in studies conducted in developing countries (Bassa & Collings, 2012), Collings (2018) decided to subject RRPQ scores to an exploratory factor analysis that employed principal components analysis and factor rotation using the varimax procedure. This analysis (Kaiser-Meyer-Olkin test = .811, Bartlett's test = .000) yielded three factors that met the study criteria for retention: an eigenvalue greater than 1, a scree plot supporting retention, a factor loading of at least .40, and the meaningfulness of identified factors. Finally, participants were asked what aspects of the study they were satisfied with and which they were not.

Two subscales of the Reactions to Research Participation Questionnaire were used (Newman et al., 2001). The subscales that were used are *Emotional Reactions* and *Personal Benefits*. The study of Newman et al. (2001) showed that both scales have a Cronbach's Alpha of 0.82 ($\alpha = .82$). These items were reformulated in order to make them suitable for

daily diary measures, similar as to Waterman et al. (2019) did. For instance, an item of *Emotional Reactions* “*The research raised emotional issues for me that I had not expected*” was changed into “*The daily diary raised emotional issues for me that I had not expected*”. “*I found participating in this study personally meaningful*” from *Personal Benefits* was changed into “*I found participating in the daily diary personally meaningful*”.

TSTI/Expert evaluation

To examine the ESM items on their suitability for ESM and measuring the symptoms of PGD, both experts on grief and experts on ESM were invited to join. When they joined a TSTI was conducted. Their input was used to make the final versions of the items. These experts could indicate on a scale from 1-4 (1=Bad, 2=Mediocre, 3=Sufficient, 4=Good) if they deemed the items suitable for ESM and also to what extent they thought items measured the corresponding symptoms. Their input was analyzed by calculating the median and range. Median and range was examined by using the statistical program SPSS.

Data-analysis

In order to examine to examine the retention- and compliance rate of the bereaved people, the percentage of completed surveys was calculated. Based on the article of Schoevers et al. (2020), bereaved people were considered a dropout when they finished less than 80% of all the surveys. Within this study, this comes down to finishing less than 56 surveys of the 70 in total. Bereaved people, who did not complete at least 80% of all the surveys, were compared with the ones who did, by looking into background and loss related variables. These variables include: gender (1= male, 2= female, 3= different), age (in years), the time since loss (in years) and the cause of death (1= Physical disease, 2= Accident, 3= Suicide, 4= Murder, 5= Different, namely...). For analysis purposes, gender (0= male, 1= female) and

cause of death (0= Natural cause, 1= Unnatural cause) were recoded because some groups needed to be merged to contain enough data. To compare the characteristics of the bereaved people who completed 56 surveys or more (completers), with the ones who did not (dropouts), a binary logistic regression was conducted.

Finally, to examine the acceptability of this study, the data forthcoming out of the Reactions to Research Participation Questionnaire (Newman, Willard, Sinclair & Kaloupek, 2001) was compared with previous research by conducting an independent sample t-test to see whether mean values found in this study were significantly different from the means found in the study of Waterman et al. (2021). In order to compare the means, the total of the answers on the four items of a subscale were added together and then divided by four to measure its mean. Waterman et al. (2021) examined whether it was acceptable to assess intimate partner violence with daily diaries. They used 923 undergraduate students in a 3-week daily diary study. The means were compared using an online calculator (<https://www.socscistatistics.com/tests/studentttest/default.aspx>).

Results

Characteristics of experts

In total five experts participated. Four of these experts were Assistant Professor and one is a PhD-student. They all worked at universities, the PhD-student also worked in clinical practice. Three of these experts had experience with ESM research, ranging from three to eight years of experience. One had four years of experience with research or treatment on grief and one expert had two years of ESM experience and 10 years of experience with research or treatment of grief.

Suitability of measuring PGD symptoms in daily life according to experts

The experts rated on a scale from 1 (bad) through 4 (good) to what extent the ESM-items measured the corresponding symptom and to what extent they were suitable for an ESM study. All converted items were deemed sufficient or good, based on the median. Except for the item “... *it felt like a part of me died with him/her*”(Identity disruption). The experts thought that item was not sufficient (median = 2) regarding the suitability for daily measures, because it would probably lack fluctuation.

Table 1

Overview of the median (range) of the answers of experts per item (n= 5)

<i>ESM item (In the past 3 hours/since waking up...)</i>	Symptom	Accuracy in assessing symptom, median (range)	Suitability for ESM items, median (range)
<i>... I felt a very strong</i>	Intense	4 (2 - 4)	3 (2 - 4)

<i>longing for him/her</i>	yearning/longing for the deceased person		
<i>... I had suddenly emerging thoughts and images that had to do with his/her death</i>	Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)	3 (2 - 4)	4 (4 - 4)
<i>... it felt like a part of me died with him/her</i>	Identity disruption since the death (e.g., feeling as though part of oneself has died) since the death	3 (2 - 4)	2 (2 - 3)
<i>... it felt unreal that he/she is dead</i>	Marked sense of disbelief about the death	4 (3 - 4)	4 (3 - 4)
<i>... I avoided places, objects or thoughts that remind me that he/she is dead</i>	Avoidance of reminders that the person is dead	4 (2 - 4)	4 (2 - 4)

<i>... I had intense feelings of emotional pain, sadness or waves of grief</i>	Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death	3 (2 - 4)	4 (3 - 4)
<i>... I felt bitter or angry about his/her death</i>	Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death	4 (3 - 4)	4 (4 - 4)
<i>... I had difficulty doing anything (e.g., studying, working, social activities, sports, hobbies)</i>	Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursuing interests, or planning for the future)	3 (2 - 3)	3 (2 - 3)
<i>... I felt numb</i>	Emotional numbness (absence or marked reduction of emotional experience) as a result of the death	4 (3 - 4)	4 (3 - 4)
<i>... I found life empty</i>	Feeling that life is	4 (3 - 4)	3 (3 - 4)

<i>and meaningless</i>	meaningless as a		
<i>without him/her</i>	result of the death		
<i>... I felt alone or felt</i>	Intense loneliness as	4 (2 - 4)	4 (2 - 4)
<i>a distance from other</i>	a result of the death		
<i>people</i>			

Based on the data, there were still possibilities for improvement of the converted items. Table 2 shows the process of this conversion by first showing the original items of the English version of the TGI-SR+, the proposal of ESM items on which the experts gave their feedback and then the final ESM items that were used in the study. Item 1 is translated literally from Dutch to be able to show the process of conversion.

Feedback that item 1 received was that the word “very” should be removed. In the study, participants could rate their experience regarding the items on a scale on which they could mark how much they longed for the deceased loved one. Therefore, a word like “very” is not necessary as participants could indicate precisely how much they longed for the deceased one. Item 2 was changed because thought and images are not the same and therefore it was changed into “... thoughts OR images”. Item 6 had the word “intense” in it. That would remove input from participants who had for example only little feelings of emotional pain. Moreover, to make this item easier to understand for participants, the word “sadness” was used (instead of emotional pain and waves of grief). The feedback on item 8 was that the item should be related to the bereavement; otherwise a participant could be passive because of other factors (e.g. depression). That is why “... because of his/her death” was added. Next to that, the corresponding symptom “Difficulty reintegrating into one’s relationships and activities after the death” highlights a major role for relationships. That is why “social

activities" was then moved to the front of the examples. For a full overview of the feedback, see appendix Table 1 to Table 11.

Table 2

Overview of the PGD symptoms, items of the TGI-SR+ English version, proposed ESM items to experts and adapted ESM items after the feedback

PGD DSM-5-TR symptom	TGI-SR+ item (<i>In the past month...</i>)	ESM item as proposed to experts (<i>In the past three hours/since waking up...</i>)	Adapted ESM-items after receiving the feedback (<i>In the past three hours/since waking up</i>)
Intense yearning/longing for the deceased person	<i>... I found myself longing or yearning for the person who died</i>	<i>... I felt a very strong longing for him/her</i>	<i>... I felt a strong longing for him/her</i>
Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)	<i>... I had intrusive thoughts or images related to the person who died</i>	<i>... I had intrusive thoughts and images that had to do with his/her death</i>	<i>... I had intrusive thoughts or images that had to do with his/her death</i>

Identity disruption since the death (e.g., feeling as though part of oneself has died) since the death	... <i>It felt as if a part of me has died along with the deceased</i>	... <i>It felt as if a part of me died along with the deceased</i>	No adjustments
Marked sense of disbelief about the death	... <i>It felt unreal that he/she is dead.</i>	... <i>It felt unreal that he/she is dead</i>	No adjustments
Avoidance of reminders that the person is dead	... <i>I avoided places, objects, or thoughts that reminded me that the person I lost has died</i>	... <i>I avoided places, objects, or thoughts that reminded me that the person I lost has died</i>	No adjustments
Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death	... <i>I experienced intense emotional pain, sadness or pangs of grief</i>	... <i>I experienced intense emotional pain, sadness or pangs of grief</i>	... <i>I experienced sadness about his/her death</i>
Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death	... <i>I felt bitterness or anger related to his/her death</i>	... <i>I felt bitterness or anger related to his/her death</i>	No adjustments
Difficulty reintegrating into one's relationships and activities after	... <i>I felt that moving on (e.g., making new friends, pursuing new interests) was</i>	... <i>I had difficulty starting to do anything (e.g., studying, working,</i>	... <i>I had difficulty starting to do anything (e.g. social activities, studying,</i>

the death (e.g., problems engaging with friends, pursuing interests, or planning for the future)	<i>difficult for me</i>	<i>social activities, sports, hobbies)</i>	<i>working, sports, hobbies) because of his/her death</i>
Emotional numbness (absence or marked reduction of emotional experience) as a result of the death	<i>... I felt emotionally numb</i>	<i>... I felt numb</i>	<i>... I felt emotionally numb because of his/her death</i>
Feeling that life is meaningless as a result of the death	<i>... I felt that life is unfulfilling or meaningless without him/her</i>	<i>... I felt that life is unfulfilling or meaningless without him/her</i>	No adjustments
Intense loneliness as a result of the death	<i>... I felt alone or detached from other individuals</i>	<i>... I felt alone or felt a distance from other people</i>	<i>... I felt alone or a distance from other people because of his/her death</i>

Characteristics of bereaved people

In total 80 bereaved people participated. These participants were aged 20 to 84 ($M = 41.48$, $SD = 16.95$) and were 77.5% female ($n = 62$). The majority of participants were born in Germany (57.5 %, $n = 46$), followed by people from the Netherlands (30%, $n = 32$), and one person from Ukraine and Indonesia. Most people finished college or university (60%, $n = 48$), 23.8% ($n = 19$) received a diploma with vocational education and 16.3% ($n = 13$) finished high school.

Feasibility of measuring PGD in daily life

To examine the compliance rate, the ratio of the number of ESM measurements that participants actually completed over the theoretical maximum number of self-evaluations was calculated. Eighty participants could theoretically fill in 5600 surveys if they completed all of them. With 3178 surveys filled in, this study has a compliance rate of 57%. To examine the retention rate, people who dropped out or did not finish 80% or more of all surveys were compared with the total number of participants. Of all 80 participants, 16 people finished 56 or more surveys. This means that the retention rate is 20%.

Seventy-five people were interviewed a second time and 7 of those participants said they stopped during the ESM-phase early. Reasons these seven people gave for quitting early were: receiving the same questions every day and filling in the same answers every day was irritating and not helpful for them. In their opinion there were too many measurements per day and they deemed the questions too “intense”. The latter meant that respondents did not identify themselves at all with the items, as they did not experience any psychological problems due to the bereavement.

An additional five people did not complete the second interview and are also considered dropouts. This means that out of 80 participants, 12 people (15%) dropped out literally of the study. Bereaved people who finished less than 56 surveys were also considered dropouts. Comparing the characteristics of the dropouts (n = 64) with the characteristics of bereaved people who are considered completers (n = 16), none of the comparisons showed a statistically significant finding (see Table 3).

Table 3

Overview of comparison between dropouts (n=64) and completers (n=16) based on background variables, age, time since loss, cause of death and gender

Characteristic	Dropouts	Completers	B	SE	p-value
Age, M (SD)	40.70 (17.27)	44.63 (15.76)	.014	.017	.420
Gender			.751	.819	.359
Female	48 (75%)	14 (87.5%)			
Male	16 (25%)	2 (12.5%)			
Cause of death			.060	.731	.935
Natural	52 (81.3)	13 (81.3%)			
Unnatural	12 (18.8%)	3 (18.8%)			
Time since loss in years, M (SD)	5.84 (8.08)	4.74 (4.85)	-.024	.043	.584

The acceptability of measuring PGD in daily life

To examine the acceptability of this study, the subscales *Personal benefits* and *Emotional reactions* of the Reactions to Research Participation Questionnaire (Newman, Willard, Sinclair & Kaloupek, 2001) were used. The outcomes of these subscales were then compared with a similar study that used the same subscales (Waterman et al., 2021). Regarding the subscale *Personal benefits*, this study showed lower ($M = 2.90$, $SD = 1.00$) than in the study of Waterman et al. ($M = 2.97$, $SD = 0.92$). This was not significant ($p = 0.517$). Concerning the subscale *Emotional reactions* the participants scored lower ($M = 1.55$, $SD = 0.75$) than in the similar study ($M=1.78$, $SD = 0.80$). This difference was not significant ($p = 0.249$). For an overview of these results, see Table 4

Table 4

Overview of acceptability from this study (n=75) compared with the study of Waterman et al. (2021) (n=460)

RRPQ	Mean (SD) in this study	Mean (SD) in Waterman et al., (2021)	<i>p</i> -value
Personal benefits	2.90 (1.00)	2.97 (0.92)	0.517
Emotional reactions	1.89 (1.00)	1.78 (0.80)	0.249

Discussion

The purpose of this study was to gain more insight into the application of ESM to study grief reactions in daily life of bereaved people. This is, to the best of our knowledge, the first study that does that. In order to conduct this research, we needed to convert PGD items of the TGI-SR+. Conducting a TSTI on ESM/PGD experts tested the suitability of these items. After that, the feasibility of this ESM-study was evaluated by calculating the retention- and compliance rate. Finally, the acceptability of this study was examined by comparing the results on an adapted version of the RRPQ with Waterman et al., 2019.

According to five ESM and/or grief experts, most of the converted items of the TGI-SR+ were suitable for implementation in an ESM study and also measured the corresponding PGD DSM-5-TR symptom sufficiently. However, some experts mentioned that some of the ESM-items might lack fluctuation within one day and are therefore less suitable for ESM-research. For instance, identity disruption and difficulty reintegrating into one's relationships and activities after the death might be more static experiences people have. We chose to include them anyhow, in order to cover all PGD symptoms. Future research should examine whether the experts were right regarding their opinion on these items.

Two aspects of daily diary methodologies (feasibility and acceptability) were examined with a group of participants consisting of bereaved people. Regarding the feasibility, there might be difficulty in obtaining high levels of completion- and retention rates in these kinds of studies. Unfortunately, the compliance rate in this study is considerably lower than it was in other ESM studies. About half of the possible questionnaires were finished, compared to the average of 80% found in a systematic review about feasibility and acceptability of ESM studies on severe mental disorders (Vachon et al., 2019). On average these studies had 7 assessments per day, with 23 items per assessment, for 11 days. This study included 18 items (11 PGD items and 7 contextual items), 5 times a day, for 14 days. Thus,

the amount of days our study included might partly explain the lower compliance rate.

Moreover, the retention rate is only one-fifth in total compared to the aimed ninety percent (Vachon et al., 2019). A frequent remark bereaved people gave was that this study contained too many measure points per day. They said that they were not able to fill in all self-assessments, because of responsibilities such as work. Although Vachon et al. (2019) showed that the average of 79 ESM studies included 7 assessments per day (compared to 5 assessments that our study included) and still achieved a retention rate of ninety percent in general. However, because our study had such a low retention rate, the amount of assessments could be reconsidered for future research. Next to that, some participants found the questions and their answers to them too repetitive. They mentioned receiving the same questions every day and their answers were the same too. This is in all probability because we did not focus on recruiting people with PGD. As a consequence, bereaved people were likely to fill in the lowest option (0 = Not at all) every time, as they did not experience PGD symptoms. This is in line with the fact that Lenferink et al. (2022) concluded that the TGI-SR+ is a valid measure for PGD DSM-5-TR. The questionnaire should therefore make an evident distinction between people who are grieving and people who have PGD. To substantiate the conclusion of Lenferink et al. (2022) about the TGI-SR+ being a reliable and valid measure, we recommend a more heterogeneous sample, namely participants with and without PGD for future research. As repetition is necessary for ESM and therefore can not be changed, the fewer measure points per day as mentioned before might prevent people from dropping out as a consequence of repetitiveness. Furthermore, bereaved people mentioned the items to be too intensely formulated. As a consequence, if a participant experienced a symptom only little, they still filled in the answer stating they did not experience it at all. The purpose of the ESM items was to measure PGD in daily life. As a lot of participants filled in the lowest answering option (0 = not at all) on PGD symptomatology, this might mean that the converted ESM

items accurately measure PGD, as bereaved people without this disorder should score low on these items. Also to test whether the converted ESM items of the TGI-SR+ make a distinction between bereaved people with and without PGD, future research should focus on recruiting both bereaved people with and without PGD.

Regarding the acceptability of this study, ESM might prove to be beneficial in the examination of grief in daily life, without a significant increase in negative participant reactions. The acceptability of examining PGD in daily life seems to be sufficient. Compared to prior research with people exposed to intimate partner violence (Waterman et al., 2021), our study showed insignificant differences regarding personal benefits and emotional reactions bereaved people experienced. This means that participating in an ESM study on grief in daily life is in all probability at least not more harmful than an ESM study on intimate partner violence.

Strengths and limitations

The main strength of this study is it being the first one examining whether grief can be studied in daily life. Therefore, it was of high importance to research the feasibility and acceptability of measuring such a loaded topic with multiple daily surveys. Another strength is that our study included experts on PGD and/or ESM to examine the suitability of the converted ESM items. Overall, they deemed the items sufficient regarding the measurement of the PGD symptoms and the suitability for an ESM study. These items might therefore be used in future research on PGD in daily life.

One of the limitations was that seven bereaved people, who dropped out, mentioned that the items were not relevant for them, as they did not experience PGD symptoms. They described that they started answering items without thinking. Although ESM studies require participants to think as little as possible to really capture day-to-day fluctuations, in this case

some participants became irritated because they deemed the items not relevant for themselves. Including people with PGD in future research might solve this. Another limitation is the low participant retention. It showed that it might prove difficult to obtain a low amount of attrition. However, Vachon et al. (2019) give some recommendations in order to increase participant retention. Having fewer measurements per day and higher lucrative incentives are associated with better compliance. We recommend considering such aspects for future research. Vachon et al. (2019) state that the number of days in ESM studies is not significantly associated with lower compliance. Therefore, it may be worthwhile to decrease the number of evaluations while increasing the number of days, as such obtaining a similar number of data points while maximizing compliance.

Future directions

The experts mentioned that some items might not fluctuate enough to be used in an ESM study. Symptoms of PGD such as identity disruption can remain difficult, as they most likely do not fluctuate much during a day. Future research should examine the input of the experts and the extent of fluctuation of the PGD symptoms.

For future research it could be beneficial to focus more on the recruitment of bereaved people with PGD. This could increase participant retention, as the items are then more relevant for them. Next to that, a heterogeneous sample consisting of people with and without PGD could prove beneficial by comparing the two groups to get more insight in grief and PGD in daily life.

Future research might take higher incentives and fewer measurements per day into consideration. Multiple participants mentioned the five self-assessments per day as very burdensome. This was described not only by bereaved people who dropped out from the study, but also by bereaved people who remained until the end of the study but did not finish

at least 80% of all questionnaires.

Conclusion

Overall, findings suggest that the converted items of the TGI-SR+ are suitable for use in ESM studies and are sufficient in measuring the corresponding DSM-5-TR PGD symptom according to experts. Aspects such as higher incentives and fewer measurements could increase feasibility of measuring PGD in daily life. Implementing daily diaries for examining PGD in daily life seems acceptable as evidenced by bereaved people indicating that on average they reported to not have adverse emotional reactions as a result of participating in ESM research and that they experienced some personal benefits after participation.

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Appendix

Table 1

Overview of the feedback of experts on item 1

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	Sitting there thinking for a moment. "I think if I had somebody recently who passed away, that I would have a feeling about that."	3	2	Would rephrase the question. This expert would leave the word "very" out of the item.
2	Positively worded, could identify with it. Raises questions regarding the type of death	4	4	Good item
3	Had a comment here regarding the scale: 'I assume 5 is "a little bad"' Measures very clear the symptom and is very well suited for ESM	4	4	
4	Start from not to very strong. "Very strong" does not match the scale. "Very strong desire, I very much have?" I would add the options on the scale myself.	2	2	very much, very strongly/ it is a kind of yes/no question
5	I would take a moment to ask who he/she is. 4 What does the middle mean, what does 4 mean?	4	3	"Very strong" could possibly be "strong".

Table 2

Overview of the feedback of experts on item 2

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	Can imagine this very recently after that does come up, I imagine it was a week ago. I would perhaps think more of the person themselves instead of that person's death	3	4	do think the question is well put. Preoccupation can also be continuous. I wonder why "suddenly" is included.
2	Wondering if difference between traumatic or natural death. She did like this item	2	4	I'm not sure if "suddenly emerging" and "images" cover preoccupation

3	No comments/observations	3	4	Whether it is really preoccupation, he does not know. Preoccupation has a negative connotation, this item does not. Possibly add "while I didn't want to". Thinks the item is sufficient, but this could be improved. Now the item can also measure something measure positively (think of someone who is no longer there).
4	Sits for a long time thinking about it. Doubt because of "I had sudden emerging thoughts", but did I have them very much? Is more of a yes/no answer.	4	4	Preoccupation, in my opinion, is something other than intrusive thoughts and memories
5	I would again wonder who it is about, instructing people that it is about the one who has died. Looks up questionably for a long time, but thinks it's clear	4	4	Thoughts OR images instead of AND images

Table 3

Overview of the feedback of experts on item 3

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	This is how you put it into words. For myself, it wouldn't feel that way. I don't think everyone would put it into words like that.	2	2	Try to keep something more general about identity disruption, not putting words into people's mouths. In addition, he wonders if there is going to be enough variance on this item in one day.

2	Recognizable from clients, interesting that 3 hours is included	4	3	"Fairly extreme formulation in which I wonder if it is changeable".
3	No particularities	3	2	Don't really know if this is something you have specifically in the moment, or more in general.
4	No particularities	3	2	Probably doesn't fluctuate much. It does measure the symptom, but probably not suitable for ESM
5	I would find this rather confronting if I got this several times in one day. Thinks it is an extreme formulation. Wonders if this is something people feel on a regular basis	4	3	Reads a bit like it's about the entire past 3 hours. So put this clearly in the instruction.

Table 4

Overview of the feedback of the experts on item 4

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	This I can imagine	4	3	"In this regard, I also wonder about the fluctuation over the day"
2	Also recognizable from students	4	4	Good item, measures symptom and is ESM appropriate. Clients often don't want to believe it either.
3	I can well imagine, so then I choose a 5. Tricky because it seems because I always have it then?	4	3	Clear item, really measures the symptom. For ESM, well enough. But also tricky for ESM, does this fluctuate?

4	No particularities	3	4	Is that the same "unbelief" and "unreality?".
5	Presses lips together and thinks for a while. Also this item he finds quite confronting to get several times a day	4	4	I think that one is clear. Nice and short too, asks one thing. That is good.

Table 5*Overview of the feedback of the experts on item 5*

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	It would be mostly thoughts. I find him a bit broad, sitting down looking thoughtful. The question can split up, also requires a lot of self-insight	2	4	Wonders why "places" and "objects" have been pasted in. "I find it strange that objects and places have been pasted in here. That's not the symptom itself then, maybe indirectly."
2	Looks thoughtful, has to laugh a little. A client is contradictory, he does not avoid. Looks things up, but is actually confrontational, asks out two things at once. Difficult question.	4	3	Tricky is that any memory can be painful and anything can remind a client of the deceased. Is it changeable though, especially places? Thoughts do.
3	Looks thoughtful. "Is a double question".	4	4	Very clear item, measures symptom and this is also really appropriate for ESM. Consideration: frequency scale because it is behavior.
4	"Well, if you just go to work because you	3	2	I don't know if this

have to, then you also avoid things."

is easy to measure. When do you avoid something and when do you just not do it, do you always come across these types of cues (so can you avoid in all cases)? If you don't do something, can you measure it?

5	I think it is clear in itself.	4	4	<p>Possibly not asking about places if it's just about memories?</p> <p>Here it is good that it says "or". With the word "places." Then looking at symptom, I would wonder about asking "places" out. Memories to me is something cognitive</p>
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Table 6

Overview of the feedback of the experts on item 6

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	"That emotional pain, I can imagine that's a 6".	2	4	"Why is this split into two questions? Waves of grief I find vague. This question is not about death, but about emotional pain in general"
2	"Clear question"	4	4	"Beautiful, different words. Waves of mourning especially recognizable,

				suitable for asking out several times a day."
3	"With all these questions, tricky because then it's unclear because it happened once or it happened 3 hours in a row. Neutral is also weird. Unclear scale.	3	4	Possibly tricky because "intense" is embedded in the item. There is already a qualifier in the item. What if you've had a little trouble with it. Possibly "intense" out.
4	No particularities	3	3	Really naming the emotions (including grief) is better than talking about "waves of grief," or emotional pain
5	Here I would wonder what "intense" would be. Otherwise proposal to brief participant. "Intense" is bit vague to me. As a participant, I would wonder, there are several things being asked here.	4	4	Emotional pain possibly a bit vague, briefing is important here I think. I think that the item does measure the symptom well. Also ESM appropriate. "Emotional pain" I think is a bit vague. There are more concrete examples in the sample and otherwise clearly explain to participants what emotional pain is

Table 7*Overview of the feedback of the experts on item 7*

Experts	Comments/observations	Sympto	ES	Comments/improv
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		m	M	ements
1	"Fits all of it I think, leans heavily against that emotional pain".	4	4	Wonder why this was pulled apart (Item 6 and 7). And why, instead of just grief, "emotional pain" was chosen. Bitter is taken literally, though.
2	Bitter or angry, looks up to think about it	4	4	Measure symptom well. Anger may vary, so ESM appropriate.
3	That is a really clear and easy question	4	4	So it does have qualification in it, but it doesn't suffer from this. In this it is more like emotion. Good item, very suitable for ESM
4	No particularities	3	4	"This one seems more logical than the one in item 6, I would use those examples because that is how people really say it I think"
5	Also here, two somewhat different things are being asked here. Would confuse me a bit. One is about somewhat more depressed feelings and angry is a little different. There are two emotions being asked	4	4	I think it is clear. It does have two definitions, but because it says OR, he likes the item anyway.

Table 8*Overview of the feedback of the experts on item 8*

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	"I suppose that's because of that mourning then. Sits here thinking about this for a long time. "I think it's something I can well imagine then".	2	3	"Social aspect is a little understated". The item says "social activities.

				Give a little more attention to relationships. Example is somewhere in the middle, while relationships are clearly highlighted in the symptom.
2	Here she has to think long and hard. "Past 3 hours, may be different again since death?".	3	4	If someone already had a diminished interest (from other causes) you won't find this out now. Maybe good to put the relationship to the death in the question, just like in the CAPS for PTSD. "Nothing is mentioned about the death, what was it like before the death".
3	Answers "Not at all" to the statement, because "you just have to work too".	3	2	Did find it a difficult item. Also like today I am working all day, did I struggle with it? It just must. Particularly in terms of working he finds these difficult, he understands him better regarding social activities etc. Had to think too much about this item, whereas with ESM it should be simple.
4	This one is tricky though, what reason you can't do anything? It is difficult to measure something you are NOT doing.	2	2	Not clear that it is loss/relationship related - may need

to be made clear that it is.

5	“I think that one is clear in itself, but could be more concrete. Was I physically unable to do something or mentally?”.	3	3	Difficulty with something is possibly something vague (does that mean no motivation, or that you are physically unable, ...?) Otherwise give clear instruction again
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Table 9
Overview of the feedback of the experts on item 9

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	"This I can well imagine".	4	4	I think this is a good one. "Stunned" I think is a good translation of the symptom.
2	This item the expert recognizes	3	4	“Stunned” though nice, but maybe add the word "flat", also suitable for ESM.
3	Is a clear item	4	4	This is just a good item, measures the affect immediately.
4	Clear item	4	4	This one is good though, is it possible to make "him/her" more personal (by tuning in to the deceased person)?
5	Clear item.	3	3	On "numb" I would question whether I would find that word clear. When

explaining,
indicate clearly.
Perhaps you could
indicate,
"emotionally
numb".

Table 10

Overview of the feedback of the experts on item 10

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	More of a cognitive question. Would be a question were participants would think: is that so? And then because of that question think about it, is a bit induced. ESM is more about easy questions that require no thinking.	3	3	Again risk of little fluctuation or very strong correlation with e.g. grief. Wonder why different wording than in the symptom.
2	I recognize that very much.	4	3	Mostly "without meaning" beautiful, matches well. Again quite extreme, does it fluctuate? Use "Does life have meaning" in the formulation. I can imagine that the thought "life has no meaning" fluctuates more than emptiness/meaninglessness
3	Flaps arms, laughs a little, thinks it's too big of a question	4	3	Measure the symptom well. In terms of ESM, I would try, but again: does this fluctuate? Still a pass, though.
4	You can answer this on such a scale.	4	4	Remove "him/her?" I also came across this earlier, possibly programming

				depending on deceased person to make it more personal
5	Again two words "empty" and "without meaning" but they are similar. So that's not a problem. Do find 10 items already a lot and intensive as a participant	4	3	I think that one is clear. I would consider instead of "empty and meaningless" to just make it "meaningless". Otherwise you ask again to some other things. Measures well the symptom, in terms of ESM could be a little better: see suggestion

Table 11
Overview of the feedback of the experts on item 11

Experts	Comments/observations	Symptom	ESM	Comments/improvements
1	I can also well imagine.	2	2	Why is the term "loneliness" not used? Why is it not linked to death? Can imagine this being a continuous feeling and not fluctuating too much
2	I also recognize that very much	4	4	Good. May also fluctuate.
3	See, this item is clearer	4	4	Good item! And here no qualification such as "intense".
4	You can also easily measure this one.	4	4	
5	Felt distance from other people I would not find completely clear as a participant. Does this mean that. I couldn't do it, is that really the same as alone? Find that a little vague.	3	3	Did I feel distance from other people, don't know if that's so obvious. Possibly "did I not feel connection with other people"

as an alternative?
What does it mean
"I feel distance
from other
people". Maybe
formulate "did I
feel alone" or "not
connected"
