

Is it acceptable and feasible to measure prolonged grief disorder symptoms in daily life using experience sampling methodology?

L.I.M. Lenferink^{a,b,c,*}, J.H.W. van Eersel^{b,1}, M. Franzen^{c,d,1}

^a Department of Psychology, Health & Technology, Faculty of Behavioural Management and Social Sciences, University of Twente, P.O. Box 217, 7500 AE Enschede, the Netherlands

^b Department of Clinical Psychology, Faculty of Social and Behavioural Sciences, Utrecht University, P.O. Box 80140, 3508 TC Utrecht, the Netherlands

^c Department of Clinical Psychology and Experimental Psychopathology, Faculty of Behavioral and Social Sciences, University of Groningen, Grote Kruisstraat 2/1, 9712 TS Groningen, the Netherlands

^d Department of Psychology, Education & Child Studies, Erasmus School of Social and Behavioural Sciences, Erasmus University Rotterdam, 3062 PA Rotterdam, the Netherlands

ARTICLE INFO

Keywords:

Prolonged grief
Bereavement
Experience sampling
Diary
Ecological momentary assessment
Loss

ABSTRACT

Introduction: Current grief research is dominated by cross-sectional studies assessing prolonged grief disorder (PGD) symptoms retrospectively. Examining grief in daily life, using Experience Sampling Methodology (ESM), may advance the field. Because of the lack of ESM-research on PGD, we evaluated the acceptability and feasibility of assessing PGD symptoms in daily life of bereaved people.

Materials and methods: ESM-items assessing PGD symptoms were developed using cognitive interviewing with five ESM/grief experts. Eighty bereaved adults completed these ESM-items five times a day for two weeks. Before and after this ESM-phase, interviews were administered assessing PGD retrospectively (using the Traumatic Grief Inventory-Clinical Administered). *t*-tests were performed comparing symptom severity of aggregated moment-to-moment recall (using ESM-items) with retrospective recall (based on interviews) of PGD symptoms. Acceptability of participating in ESM-research (assessed with the Reactions to Research Participation Questionnaire) was examined using descriptive statistics. Feasibility was evaluated by reporting compliance and retention rates.

Results: Minor changes were made to the ESM-items based on expert interviews. Average levels of aggregated moment-to-moment recall of the symptoms “yearning” ($d = -1.04$), “preoccupation with the deceased” ($d = -0.91$), “marked sense of disbelief” ($d = -0.43$), and “intense loneliness” ($d = -0.28$) were lower compared with retrospective recalling these symptoms. On average, bereaved people were neutral about personal benefits gained through participation in this EMS-study. They indicated that participation did not raise emotional reactions. Compliance and retention rates were 60% and 65%, respectively.

Discussion: Our findings indicate that whereas compliance and retention is challenging, using ESM to study PGD symptoms in daily life might be useful. Nevertheless, more research is needed.

1. Introduction

The death of a loved one is a potential traumatic life event. Most people adapt to a loss without professional mental health support, but for some the grief process is characterized by intense and long-lasting grief reactions that disrupt daily life [21]. These disabling grief reactions are labelled Prolonged Grief Disorder (PGD) in the text-revised fifth edition of the Diagnostic and Statistical Manual of Mental

Disorders (DSM-5-TR; [1]) and the 11th edition of the International Classification of Diseases (ICD-11; [33]). About 10% of bereaved people develop PGD [17].

Research on severity of PGD symptoms has mostly been conducted by assessment at one timepoint using surveys or interviews. When using this method, participants are usually asked to rate to what extent they have experienced grief reactions (e.g., “intense longing for the deceased”) during the past month [26]. Retrospectively recalling

* Corresponding author at: Department of Psychology, Health & Technology, Faculty of Behavioural Management and Social Sciences, University of Twente, P.O. Box 217, 7500 AE Enschede, the Netherlands.

E-mail address: l.i.m.lenferink@utwente.nl (L.I.M. Lenferink).

¹ Shared authorship.

<https://doi.org/10.1016/j.comppsy.2022.152351>

symptoms has shown to be prone to bias. For instance in depression research, it has been found that people with depression tend to overestimate their depression levels, while people without depression tend to underestimate their depression levels when asked about these symptoms during the past weeks [3]. Recall bias is explained as the lack of accuracy in memory because people cannot draw information directly from their episodic memory [2]. Assessing symptoms in daily life overcomes this recall bias. One way to study psychological phenomena in daily life is using Experience Sampling Methodology (ESM) [11]. ESM is an intense longitudinal data collection method whereby people repeatedly answer questions, usually multiple times per day, for a certain study period [19].

To the best of our knowledge, ESM has not been used before to assess PGD symptoms in daily life. Assessment of PGD symptoms in daily life has several advantages. Firstly, it may give a more accurate assessment of severity of PGD symptomatology due to its ecological validity [24]. Secondly, it allows for the examination of contextual factors associated with increased PGD levels, for instance by examining to what extent increased PGD levels are related to social and physical activities (e.g., “What are you doing? With whom are you?”), which may inform the theorization of grief. Thirdly, it offers new opportunities for treatment of PGD. By using ESM to study PGD symptoms in daily life, treatments can be provided in daily life as well. ESM-interventions have shown to be promising in treating a variety of mental health problems [13,19,29–31]. However, the promises of ESM-interventions in PGD remain to be explored.

Studying grief in daily life using ESM may also have potential downsides. A qualitative study among 22 patients with various mental health conditions showed that completing multiple assessments per day was expected to be too burdensome when assessments are too frequent, too long, or when items are perceived as irrelevant [7]. A second potential issue in ESM research is related to reactivity effects, which may occur when intensive self-report changes the investigated phenomenon [8]. Being constantly reminded of one’s own symptoms, or in the case of PGD being reminded of the loss and one’s grief reactions, may worsen symptomatology [7]. However, using ESM for assessment of symptomatology could also serve as self-monitoring of symptoms, which has shown to improve symptomatology [29]. A third challenge in ESM research is to retain high compliance (i.e., percentage of actual completed measures relative to the maximum possible completed measures) and retention rates (i.e., percentage of participants that did not dropout of the study). A meta-analysis including 79 ESM studies among various patient groups showed a pooled compliance rate of 79% and retention rate of 93% [27]. These 79 ESM studies included on average 7 assessments per day (including 23 items per assessment) for 11 days.

Nevertheless, there are various options to increase the feasibility of ESM research. When studying phenomena in daily life using ESM, it has been recommended to use a brief item-pool to limit the burden for participants. For instance, it has been recommended to not use >30 items in total per measurement [29]. When developing ESM-items it is important to use items that are susceptible to change [8]. Using items from traditional surveys/interviews that require retrospective recall over the last weeks or months are therefore not applicable to assess on a daily basis. Furthermore, it is important that ESM-items show face and content validity [9]. Face-validity concerns the extent to which an instrument is subjectively covering the concept that it supposed to measure. One way to test face-validity is by cognitive interviews [22]. During these cognitive interviews, respondents think out loud while reading and answering the questions. Furthermore, face-validity can be evaluated by asking experts to what extent they think the items are comprehensible and acceptable to use in ESM-research. Content validity relates to the degree that the measure represents and captures all facets of the construct it supposes to measure. One way of testing this is by asking participants to what extent they think the items represent a certain construct. While many ESM-researchers emphasize the importance of evaluating the validity of ESM-items, it is often neglected,

which may lead to biased results [9].

In sum, despite corresponding challenges, assessment of PGD symptoms in daily life using ESM offers new and important research possibilities. The first aim of the current study was to develop ESM items to assess PGD symptoms in daily life (Part 1). In doing so, we used cognitive interviewing to evaluate the comprehensibility of the items among grief and ESM experts. In part 2, our aim was to explore possible differences in severity of PGD symptoms in bereaved people by comparing scores on moment-to-moment recall (using ESM-items) with retrospective recall (based on interviews) of PGD symptoms using methods from prior research [3]. Our third aim was to evaluate the acceptability of assessing PGD symptoms in daily life using ESM, by asking bereaved people about their experiences with completing daily diary assessments. Our fourth aim was to explore possible reactivity effects, by comparing interview-based PGD levels before and after the ESM-phase. Our last aim was to evaluate the feasibility of assessing PGD symptoms in daily life using ESM, in terms of compliance and retention rates and correlates thereof.

2. Materials and methods

2.1. Participants and procedures

This study is part of the Grief in Daily life (Grief-ID) project which aims to examine and treat PGD symptoms in daily life. In part 1, ESM and grief experts from the social network of the authors were invited to take part in the cognitive interviews. ESM experts had to have a PhD and had to have experience with conducting and publishing ESM research in the field of psychiatry/psychology. Grief experts had to have completed their PhD dissertation on the topic of grief or had to work as a licensed psychologist in treating people with PGD. We stopped inviting experts for the cognitive interviews once we did not receive new information from the interviewees. The cognitive interviews were undertaken by a trained interviewer in November 2021 using a video-call program. All experts signed an informed consent form prior to participation. Experts did not receive any compensation in exchange for participation. Ethical approval for conducting Part 1 was obtained by the ethics committee of the University of Twente (number: 211167).

In part 2, adults who lost a loved one (e.g., partner, family member, or friend) at least three months earlier were eligible to sign up for the study. Bereaved people needed to be fluent in Dutch or German and to possess a smartphone in order to participate. People who had a high suicide risk or had been diagnosed with a psychotic disorder (both assessed with single items at baseline) were excluded from participation. People were recruited using social media advertisements in social networks of the research team and by posting recruitment materials on websites for bereaved people. Data collection took place from January till March 2022.

After reading the information letter, people signed an informed consent form and were then contacted by one of the trained interviewers (all master-level psychology students) to schedule a telephone interview (T1). T1 interviews lasted on average 47 min. After completion of T1 interviews, people received an instruction video explaining how to install and use the smartphone app for the ESM-phase. The Ethica app was used for collecting ESM-data (www.ethicadata.com).

During the ESM-phase, people received five beeps per day on 14 consecutive days. On each day, the first beep occurred randomly between 8.30 and 9.30 AM. Every three hours participants received a beep on their phone at semi-random time intervals (i.e., between 11.30 AM–12.30 PM, 2.30–3.30 PM, 5.30–6.30 PM and 8.30–9.30 PM). After 10 and 20 min a reminder was sent when people had not yet completed the ESM-survey. People had 60 min to complete the ESM-survey. Each survey consisted of 17 ESM-items. Completion of these items took approximately 1–2 min. When someone missed more than half of the surveys on one day (i.e., ≥ 3 surveys), the interviewer contacted that person via telephone or email to encourage them to complete future

surveys. Within two days after completing the ESM-phase, a second telephone interview (T2) was scheduled. People took part in a raffle where they could win one €50 voucher. Ethical approval for Part 2 was obtained by the University of Twente (number: 211101).

2.2. Measures

2.2.1. Background and loss-related characteristics

At T1, several questions were asked related to the background and loss circumstances of bereaved participants. In terms of background characteristics, we asked about gender (0 = *male*, 1 = *female*, 2 = *other*), date and country of birth, and highest obtained educational level (0 = *primary school*, 1 = *high school*, 2 = *vocational education*, 3 = *college*, 4 = *university*). We also asked whether the participants have received support from a psychologist, therapist, or psychiatrist related to coping with the death of their loved one (0 = *no*, 1 = *yes*) and, if yes, whether they currently still receive that support (0 = *no*, 1 = *yes*). In terms of loss circumstances, we asked about the date of the death, relationship to the deceased, cause of death (0 = *physical illness*, 1 = *accident*, 2 = *suicide*, 3 = *homicide/manslaughter*, 4 = *other, namely*), and unexpectedness of the death (1 = *completely expected* to 5 = *completely unexpected*).

2.2.2. Traumatic grief inventory-clinician administered (TGI-CA)

At T1 and T2, PGD symptoms were assessed using the TGI-CA. The TGI-CA is a 22-item interview to assess PGD symptoms as defined in DSM-5-TR as well as other definitions of a grief disorder [15]. The TGI-CA is the interview-version of the self-report measure Traumatic Grief Inventory – Self Report Plus (TGI-SR+) [14]. For the current study, items representing DSM-5-TR PGD criteria were summed (i.e., item 1, 3, 6, 9, 10, 11, 18, 19, 21, and the highest answer option on item 2 or 8). Participants were asked to rate on a scale from 1 (*never*) through 5 (*always*) to what extent they experienced each grief reaction during the past two weeks (e.g., “In the past two weeks, did you feel alone or detached from others?”). In the original TGI-CA, the time period is the “past month”. We adapted this time frame for the current study to “past two weeks” to match the time period of the ESM-phase which was also two weeks. The TGI-CA has sound psychometric properties [15]. Cronbach’s alpha for the DSM-5-TR items in this sample was 0.88 at T1 and 0.89 at T2.

Following the diagnostic scoring rule of DSM-5-TR [1], we considered probable caseness of PGD when the participant endorsed at least one out of two B criterion symptoms, ≥ 3 out of 8 C criterion symptoms, and the functional impairment criterion. Following prior research, a score of >3 represented symptom endorsement [14].

2.2.3. Reactions to research participation questionnaire (RRPQ)

To examine the acceptability of assessing PGD symptoms in daily life at T2, we used eight items from the RRPQ [20]. These items include the subscale Personal Benefits (i.e., four items e.g., “I found participating in daily diary measures in the app beneficial to me.”) and the subscale “Emotional Reactions” (i.e., four items e.g., “Participating in daily diary measures in the app raised emotional issues for me that I had not expected.”). Following prior research [32], we referred to “participating in daily diary measures in the app” in each item. For instance, “I gained insight about my experiences through research participation” was adapted to “I gained insight about my experiences through participation in daily diary measures in the app”. People were asked to rate each question on a scale from 1 (*strongly disagree*) through 5 (*strongly agree*). Psychometric properties of the original and adapted version has shown to be sufficient [20,32]. In the current study, Cronbach’s alpha levels were 0.86 for Personal Benefits subscale and 0.88 for Emotional Reactions.

2.2.4. Questions regarding dropout

We constructed three questions to assess feasibility. At T2 we first asked “Did you decide to stop answering the questions in the app prematurely? Yes/no”. When participants responded “yes”, we asked them

the following two open-ended questions: (i) “Why did you decide to stop answering the questions in the app prematurely? Please provide a brief comment” and (ii) “Do you have any suggestions for us on how to prevent people from dropping out in future research?”

2.3. Development of ESM-items

ESM-items to assess PGD symptoms as defined in DSM-5-TR were drawn from the TGI-SR+. Items from the TGI-SR+ that map onto the DSM-5-TR criteria were selected. After discussion in the research team (i.e., authors of this manuscript), consensus was reached upon how to adapt these items to ESM-items. As can be seen in Table 1, we added “in the past three hours” to each ESM item. In addition, we changed the wording of the TGI-SR+ item “I felt that moving on (e.g., making new friends, pursuing new interests) was difficult for me” to “In the past three hours, it was difficult for me to do something (e.g., studying, working, social activities, sports, hobbies)”.

These ESM-items were presented to the experts using cognitive interviewing. The cognitive interviews consisted of three steps. In step 1, the experts were asked to complete the ESM-items on a 7-point scale with 0 (*not at all*) through 6 (*very much*). While completing the items they were asked to verbalize their thoughts by thinking out loud. The interviewer does not interrupt this process, but merely observed the expert and took notes. If needed, the interviewer used probes to encourage the expert to think out loud (e.g., “Please continue verbalizing your thoughts”). The following instruction was used: “I will post the ESM items in the chat in a moment. I would like to ask you to answer the questions as if you were a participant in the study. As you read and answer the questions, I will invite you to think aloud. While you do this, I will observe you and take notes. I may also ask you for clarification.” In case the interviewer observed that the expert had difficulty understanding or answering the items, the participant was invited to elaborate on this in step 2 of the cognitive interviews (e.g., “I saw you had to reread that question twice, please tell me why?”). In step 3, experts were asked to answer two questions for each ESM-item. The first question was “To what extent do you think this item measures the symptom? (1 = *insufficiently*, 2 = *moderately*, 3 = *sufficiently*, or 4 = *well*)”. We presented the DSM-5-TR PGD symptom and the ESM-item to the expert. The second question was “To what extent do you think this item is suitable to be administered in an ESM study? (1 = *insufficiently*, 2 = *moderately*, 3 = *sufficiently*, or 4 = *well*)”. When experts answered these questions with 1 or 2, we asked them to clarify their answer. The interview script for the cognitive interview was pilot-tested among an ESM expert to test and evaluate the procedures before conducting the interviews with the five experts.

2.4. Statistical analyses

To examine to what extent ESM responses differed from retrospective recall responses, paired *t*-tests were conducted for each item separately. Before doing that, we transformed the 5-point Likert scale of the TGI-CA at T2 to a 7-point scale as was used in the ESM-items using linear transformation. Then, we aggregated the ESM responses following procedures from Ben-Zeev and Young [3]. For each ESM-item we aggregated the scores per day. When less than three out of five signals per day were complete, these ESM ratings were excluded from analysis. For each participant, all the daily scores were averaged to provide an average ESM score for the two-week ESM phase. Only those who completed ESM-items for at least 7 days were included in the analysis. A two-sided alpha level of 0.05 was used.

To examine acceptability, descriptive statistics were used for the RRPQ scales. We also ran correlation analyses between the scores on the subscales and PGD levels at T1 and T2. For examining possible reactivity effects, we compared T1 PGD levels with T2 PGD levels using paired *t*-tests.

To evaluate the feasibility of the study, we reported frequencies of compliance (i.e., % of actual completed measures relative to the

Table 1
Overview of development of ESM-items to assess PGD symptoms.

DSM-5-TR PGD symptom	TGI-SR+ item	ESM item in cognitive interview	Adapted ESM item based on experts review
Intense yearning/ longing for the deceased person.	I found myself yearning for him/her.	In the past three hours, I found myself yearning for him/her.	n/a
Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death).	I had intrusive thoughts or images related to the person who died.	In the past three hours, I had intrusive thoughts or images related to the person who died.	n/a
Identity disruption since the death (e.g., feeling as though part of oneself has died) since the death.	It felt as if a part of me has died along with the deceased.	In the past three hours, it felt as if a part of me has died along with the deceased.	n/a
Marked sense of disbelief about the death.	It felt unreal that he/she is dead.	In the past three hours, It felt unreal that he/she is dead.	n/a
Avoidance of reminders that the person is dead.	I avoided places, objects, or thoughts that reminded me that he/she is dead.	In the past three hours, I avoided places, objects, or thoughts that reminded me that he/she is dead.	n/a
Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death.	I experienced intense emotional pain, sadness, or pangs of grief.	In the past three hours, I experienced intense emotional pain, sadness, or pangs of grief	In the past three hours, I felt sad because of his/her death.
Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death.	I felt bitterness or anger related to his/her death.	In the past three hours, I felt bitterness or anger related to his/her death.	In the past three hours, I felt bitterness or anger because of his/her death.
Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursuing interests, or planning for the future).	I felt that moving on (e.g., making new friends, pursuing new interests) was difficult for me.	In the past three hours, It was difficult for me to do something (e.g., studying, working, social activities, sports, hobbies).	In the past three hours, It was difficult for me to do something (e.g., social activities, studying, working, sports, hobbies) because of his/her death.
Emotional numbness (absence or marked reduction of emotional experience) as a result of the death.	I felt emotionally numb.	In the past three hours, I felt emotionally numb.	In the past three hours, I felt emotionally numb because of his/her death.
Feeling that life is meaningless as a result of the death.	I felt that life is unfulfilling or meaningless without him/her.	In the past three hours, I felt that life is unfulfilling or meaningless without him/her.	n/a
Intense loneliness as a result of the death.	I felt alone or detached from other individuals.	In the past three hours, I felt alone or detached from other individuals.	In the past three hours, I felt alone or detached from other individuals because of his/her death.

Note. n/a = not applicable.

maximum possible completed measures). For determination of retention rate, we reported the % of participants that did not dropout of the study. Those who terminated participation early or those who completed <50% of the measurements were considered dropouts (i.e., <50% completion of measurements is a commonly used guideline for exclusion of participants in data-analyses in prior ESM-research [8]).

In addition, a binary logistic regression analysis was run with dropout vs. non-dropouts as dependent variable and background, loss-related variables, and T1 PGD levels as independent variables simultaneously. For background we included gender (0 = *male*, 1 = *female*), age of participants (in years), and educational level (0 = *other than college/university*, 1 = *university*). Concerning loss-related variables, we included cause of death (0 = *illness*, 1 = *suicide/accident/homicide/other*), relationship to the deceased (0 = *loss other than child/spouse*, 1 = *child/spouse*), and time since loss in months.

Furthermore, answers to the two open-ended questions regarding dropout at T2 were analyzed qualitatively by JvE and checked by MF, by dividing the answers into meaningful units. These units were then labelled with labels that reflected the content of these units (called subthemes). Overarching themes across these subthemes were extracted (called main themes).

3. Results

3.1. Characteristics of experts

Five experts evaluated the ESM-items in cognitive interviews (see Supplemental Materials Table 1 for characteristics of the experts). Four out of five experts worked as an academic, namely as assistant-professor. One expert was a PhD-student and scientist-practitioner. Two experts had ≥ 4 years of experience with research and/or treatment of PGD. Four experts had 2 through 8 years of experience with ESM research.

3.2. Development ESM-items to assess PGD symptoms in daily life based on expert reviews

During the cognitive interviews with experts, no issues were raised regarding the comprehensibility of the items. All experts completed the ESM-items, while thinking out loud and interpreted the questions as we intended. Subsequently, for each item, we assessed to what extent the expert thought the specific item was covering the PGD symptom accurately, as defined in DSM-5-TR, and to what extent the item was suitable to assess in an ESM-study (see Table 2).

As can be seen in Table 2, none of the experts rated an item as insufficient in terms of accuracy or suitability. Consequently, only relatively minor adaptations were made to 5 out of 11 ESM-items (see Table 1). These adaptations included an explicit referral to the death of a loved one in the ESM-items (three items did not initially refer to this). For instance, "In the past three hours, I felt emotionally numb." was adapted to "In the past three hours, I felt emotionally numb because of his/her death." Experts remarked that for the symptom "Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursuing interests, or planning for the future)" the emphasis on social relationships was not sufficiently captured with our initial ESM-item. We therefore made changes to this item. The last change we made was related to the item measuring the symptom "Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death." This symptom was split up in two ESM-items (one referring to anger and one referring to sorrow). A comment was made that the item capturing sorrow could be formulated simpler to make it more suitable for ESM-research.

3.3. Characteristics of bereaved people

In total, 80 bereaved people completed the T1 interview and started the ESM-phase. See Table 3 for an overview of the characteristics. In

Table 2
Comprehensibility and suitability of ESM-items based on expert ratings ($N = 5$).

Item	Median accuracy capturing DSM-5-TR symptom	Observed range	Median suitability for ESM-research	Observed range
In the past three hours, I found myself yearning for him/her.	4	2–4	2	2–4
In the past three hours, I had intrusive thoughts or images related to the person who died.	3	2–4	4	4–4
In the past three hours, it felt as if a part of me has died along with the deceased.	3	2–4	2	2–3
In the past three hours, It felt unreal that he/she is dead.	4	3–4	4	3–4
In the past three hours, I avoided places, objects, or thoughts that reminded me that he/she is dead.	4	2–4	4	2–4
In the past three hours, I experienced intense emotional pain, sadness, or pangs of grief	3	2–4	4	3–4
In the past three hours, I felt bitterness or anger related to his/her death.	4	3–4	4	4–4
In the past three hours, It was difficult for me to do something (e. g., studying, working, social activities, sports, hobbies).	3	2–3	3	2–4
In the past three hours, I felt emotionally numb.	4	3–4	4	3–4
In the past three hours, I felt that life is unfulfilling or meaningless without him/her.	4	3–4	3	3–4
In the past three hours, I felt alone or detached from other individuals.	4	2–4	4	2–4

sum, about three out of four participants were female. The youngest participant was 20 years old and the oldest was 84. Two-thirds of the participants were born in Germany and two-thirds had a college or university degree. Four out of five people lost a loved one due to an illness. Time since loss varied from three months to 46 years. In half of the cases, the people lost a parent. At T1, two out of 80 participants (2.5%) met criteria for probable PGD using the diagnostic scoring rule for DSM-5-TR.

Table 3
Characteristics of bereaved people ($N = 80$).

Gender, N (%)	
Male	18 (23)
Female	62 (78)
Other	0 (0)
Age in years, M (SD)	
	41.51 (16.96)
Country of birth, N (%)	
Germany	46 (58)
The Netherlands	32 (40)
Other	2 (2)
Level of education, N (%)	
Lower than college/university	32 (40)
College/university	48 (60)
Cause of death, N (%)	
Natural cause (e.g., illness)	65 (81)
Suicide	6 (8)
Accident	1 (1)
Homicide	1 (1)
Other	7 (9)
Unexpectedness of the death, M (SD)	
	3.30 (1.60)
Deceased relative is my..., N (%)	
Parent	37 (46)
Grandparent	16 (20)
Partner/spouse	10 (13)
Sibling	4 (5)
Friend	2 (3)
Child	1 (1)
Grandchild	1 (1)
Other	9 (11)
Time since loss in months, M (SD)	
	67.78 (90.40)
Received professional grief support, N (%)	
	26 (33)
Currently receiving professional grief support, N (%)	
	7 (9)

Note. M = mean, SD = standard deviation.

3.4. Moment-to-moment versus retrospective recall of PGD symptoms

Fifty-four people completed at least three out of five ESM-surveys for at least 7 out of 14 days, completed the T2 interview, and were therefore included in the analysis regarding the difference in severity of PGD symptoms between moment-to-moment and retrospective recall. Four out of eleven items differed significantly in terms of severity levels. The average severity levels of aggregated moment-to-moment recall of the symptoms “yearning” ($d = -1.04$), “preoccupation with the deceased” ($d = -0.91$), “marked sense of disbelief” ($d = -0.43$), and “intense loneliness” ($d = -0.28$) were lower compared with the retrospective recall of these symptoms (see Table 4).

3.5. The acceptability of assessing PGD symptoms in daily life using ESM

At T2, 75 people completed four items about whether they experienced personal benefits regarding their participation in daily diary measures in the app. The mean item score was 2.90 ($SD = 1.00$), which reflects a neutral response (i.e., response option 3 was ‘neutral’). They also responded to four items about whether participation in daily diary measures in the app raised emotional reactions. The mean response was 1.89 ($SD = 1.00$), which indicated that people overall did not agree with this (i.e., response option 2 was ‘disagree’). See Fig. 1 for an overview of all responses.

The associations between agreement with personal benefit as a result of participating in daily diary measures and PGD levels at T1 and T2 were moderate, positive, and significant (T1 $\rho = 0.44$, $p < .001$; T2 $\rho = 0.42$, $p < .001$). Associations between agreement with emotional reactions as a result of participating in daily diary measures and PGD levels at T1 and T2 were strong, positive, and significant (T1 $\rho = 0.54$, $p < .001$; T2 $\rho = 0.68$, $p < .001$).

3.6. Exploration of possible reactivity effects

T1 and T2 DSM-5-TR PGD levels were compared among 75 people

Table 4
Moment-to-moment versus retrospective recall of PGD symptoms ($N = 54$).

DSM-5-TR PGD symptom	Moment to moment recall		Retrospective recall		<i>t</i> -test
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Intense yearning/longing for the deceased person.	0.56	0.96	1.61	1.51	$t = -7.63$ (53), $p < .001$
Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death).	0.59	0.84	1.64	1.55	$t = -6.67$ (53), $p < .001$
Identity disruption since the death (e.g., feeling as though part of oneself has died) since the death.	0.38	0.95	0.42	1.07	$t = -0.37$ (53), $p = .712$
Marked sense of disbelief about the death.	0.47	0.82	0.97	1.43	$t = -3.13$ (53), $p = .003$
Avoidance of reminders that the person is dead.	0.31	0.63	0.33	1.00	$t = -0.23$ (53), $p = .819$
Intense emotional pain (e.g., sorrow) related to the death ^a	0.84	1.17	0.92	1.41	$t = -0.69$ (53), $p = .494$
Intense emotional pain (e.g. anger, bitterness) related to the death ^a	0.34	0.72	0.39	0.84	$t = -0.52$ (53), $p = .603$
Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursuing interests, or planning for the future).	0.38	0.91	0.28	0.88	$t = 0.93$ (53), $p = .358$
Emotional numbness (absence or marked reduction of emotional experience) as a result of the death.	0.33	0.78	0.31	0.89	$t = 0.21$ (53), $p = .835$
Feeling that life is meaningless as a result of the death.	0.38	1.00	0.31	1.10	$t = -0.11$ (53), $p = .914$
Intense loneliness as a result of the death.	0.42	1.00	0.75	1.29	$t = -2.04$ (53), $p = .047$

Note. DSM-5-TR = text-revised fifth edition of the Diagnostic and Statistical Manual of Mental Disorders; PGD = prolonged grief disorder. ^aIn DSM-5-TR this symptom is formulated as follows "Intense emotional pain (e.g. anger, bitterness, sorrow) related to the death." Following prior research [14], we assessed this symptom with two items; the first item focuses on sadness, the second item focuses on anger.

who completed both interviews. On average the PGD levels were higher ($d = 0.79$) at T1 ($M = 19.15$, $SD = 7.06$) compared with T2 ($M = 15.89$, $SD = 0.42$). This difference was found to be significant ($t = 6.86$ ($df = 74$), $p < .001$).

3.7. Feasibility of assessing PGD symptoms in daily life using ESM

In terms of absolute compliance rates, we found that on average 39.88 ($SD = 17.37$) measurements were completed. This means that on average 57% of measurements were completed. Due to two technical errors — i.e., (1) during one weekend, in the 3 months data-collection phase, participants did not receive notifications on their phone and (2) some participants received <5 measurements on day 14 of the ESM-phase — some measurements were not sent to participants. When adjusting for this, the weighted compliance rate was 60%.

In terms of retention rate, 52 people (65.0%) completed at least 50% of the measurements. At T2, 7 out of 75 people who completed T2 reported they terminated their participation in the ESM-phase early; only

1 of them completed >50% of the measurements. Thus, in total 29 people (36%) were considered dropouts.

Differences between people who did and did not dropout from the study were examined in terms of background and loss-related characteristics and PGD levels at T1. None of these variables were significantly related to the likelihood of dropping out of the study (see Supplemental Materials Table 2).

3.8. Reasons for dropout from the perspectives of bereaved people

At T2, seven participants answered 'yes' on the question to indicate whether they stopped answering the questions in the app prematurely. Based on their answers about why they had decided to stop answering questions in the app two categories emerged, namely 1) answering the questions was experienced as too repetitive ($n = 5$) and 2) they experienced technical issues ($n = 2$).

When we asked these seven participants about suggestions to prevent dropouts in future research, five categories emerged when analyzing their responses, namely 1) adjust the questions based on the provided answers ($n = 2$), 2) reduce the number of measurement occasions per day ($n = 2$), 3) make the questions less repetitive by changing the content or the order of the items daily ($n = 1$), 4) add questions that measure normal grief in addition to the PGD symptoms ($n = 1$), and 5) make sure the app-notifications are turned on ($n = 1$).

4. Discussion

The aim of this study was to examine to what extent assessing PGD symptoms in daily life of bereaved people is acceptable and feasible. In doing so, we analyzed interview-data collected among five ESM and grief experts and 5600 datapoints by 80 bereaved people collected via ESM. In addition, before and after the ESM-phase interview-based assessment of PGD symptoms took place. This is to our knowledge the largest ESM study among bereaved people. Moreover, this is also the first study examining PGD symptoms in daily life.

We started with developing ESM items to assess PGD symptoms, as defined in DSM-5-TR [1], using items from an existing self-report measure, the TGI-SR+ [14]. The TGI-SR+ assesses PGD levels as experienced in the past month. We adapted this time-frame in the ESM-items by referring to the past 3 h. Based on cognitive interviews with five ESM and/or grief experts, small adjustment to the wording of the items were made. Overall, the experts rated the ESM-items as accurate in terms of measuring the corresponding PGD symptom. The experts also indicated that they generally think that the proposed items are suitable for use in ESM-research. These findings offer first support for face- and content-validity of the ESM-items assessing PGD symptoms in daily life.

In the second part of this study, we compared scores on moment-to-moment recall (based on aggregated ESM-responses over the two-week ESM period) and retrospective recall of interview-based PGD symptoms referring to the past two weeks assessed after the ESM-phase. The comparisons showed that for four out of 11 symptoms the average severity levels of aggregated moment-to-moment recall were significantly lower than for retrospectively recalling over the same time period. No significant differences were found for the other PGD symptoms. This aligns with depression research, indicating that retrospective recall of symptoms is prone to bias [3]. Our findings offer tentatively support that moment-to-moment assessment of PGD symptoms minimizes the risk of recall bias, which may result in more accurate assessment of PGD symptomatology.

More specifically, large differences were found for the PGD symptoms "yearning for the deceased" and "preoccupation with thoughts or memories of the deceased". Small differences were found for marked sense of disbelief about the death and intense loneliness after loss. Yearning for, and being preoccupied with, the deceased form the first symptom cluster in DSM-5-TR PGD (i.e., one of them should be present according to the diagnostic scoring rule) and are often considered the

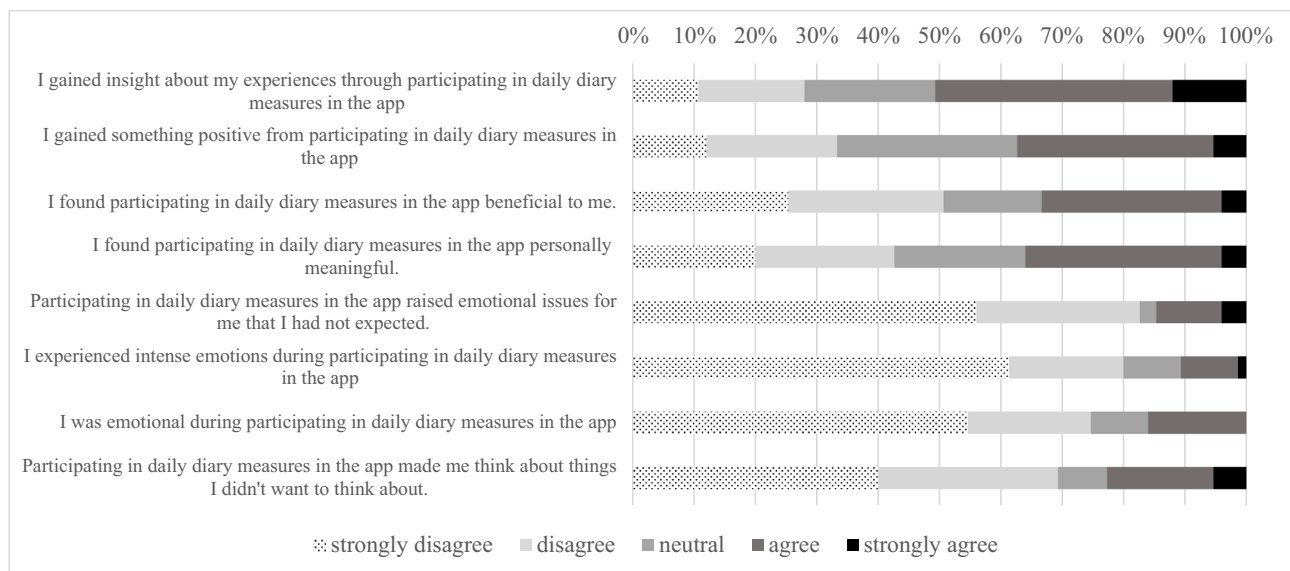


Fig. 1. Extent of agreement with reactions to participating in the daily diary measures in the app ($N = 75$).

hallmark symptoms of disordered grief [18,23,25]. Moreover, these symptoms are also the most commonly reported symptoms in bereaved people; for instance, people reported higher item means for these symptoms compared to other symptoms [5]. Based on latent class analyses [4,10,16] and item response theory [12,23], it is often shown that these symptoms do not distinguish well between people with or without PGD. In the present study, we showed, for the first time, that these two symptoms seem biased when assessed retrospectively, because people tend to overestimate the severity of these symptoms.

One possible reason for overestimating the severity of these two symptoms, when assessed retrospectively, may have to do with socially desirable responding. It is likely that people tend to overestimate the extent in which they long for, and think about, the deceased because that is more socially accepted than reporting that you do not experience these reactions. When asking about these reactions during the past two weeks, people may tend to overreport these symptoms compared with asking whether these reactions were experienced during the past three hours. However, more research is needed to test this assumption.

Our third main finding was that bereaved people were neutral about whether they found completing daily diary measures in the app personally beneficial, but they also indicated that it did not raise any emotional issues for them. In other words, there is no indication that participation in an ESM-study assessing PGD symptoms is harmful for participants. This aligns with findings from prior research, indicating that participation in ESM-research is safe, feasible, and not too burdensome [7,32]. It should be noted that the vast majority of our sample did not experience PGD. We found that increases in PGD levels were associated with higher positive reactions (i.e., personal benefits), but also higher intensity of emotional reactions. Consequently, it is plausible that people with PGD would benefit more from participation in ESM-research than people without PGD, while they may also find participation more emotional.

One of these benefits of participating in ESM-research might be an increase in insights in one's own grief reactions through self-monitoring. Self-monitoring of symptoms has been related to reduced symptomatology across various patients groups and settings [29]. Based on the comparisons between severity of interview-based PGD levels before and after the ESM-phase, we found indications that this might also be the case for bereaved people. After completing the two-week ESM-phase people reported significantly lower overall interview-based PGD levels compared to two weeks earlier. Pending replication of our findings in controlled trials, self-monitoring of PGD symptoms using ESM might be

useful as a first-step treatment to prevent or treat PGD, before referral to more specialized treatment is indicated.

Our last aim was to evaluate the feasibility of assessing PGD symptoms in daily life, in terms of (correlates of) compliance and retention rates. We found that, on average, 60% of the measures were completed. This rate is relatively low compared with the average 79% compliance rate found in a meta-analysis by Vachon et al. [27]. Furthermore, two-third of the participants in our study completed at least 50% of the measurements. This retention rate is also relatively low compared with average retention rates of 93% found in prior research [27]. When looking at correlates of dropout, we did not find support that background or loss-relates characteristics were related to an increase risk of dropout. While our sample size was relatively low for these group-comparisons, which increased type II error rates, it is likely that other factors may play a more prominent role in why people discontinue with completing daily diary measures. People who terminated early mentioned that answering the ESM-items was too repetitive and they suggested to personalize the items and/or to reduce the number of measurement occasions. Research on personalizing ESM diaries to meet the needs of psychiatric non-bereaved patients is underway [6]. In case these approaches seem to benefit clinical utility, it would be worthwhile to implement them in grief research as well. Moreover, it has been shown that higher incentives, higher time intervals between successive measurement occasions, and fewer evaluations per day were related to higher compliance rates in ESM-research in various patient groups [27]. Offering each participant an incentive and reducing the number of measurements per day may likely increase compliance and retention rates in future ESM studies in bereaved people.

Several limitations should be taken into account when interpreting our findings. The ESM-items assessing PGD symptoms were evaluated in cognitive interviews with five experts, of which only one worked as a grief therapist. Including more clinicians might have provided a more well-rounded picture of the quality of these ESM-items. While our sample size of 80 participants is relatively high for an ESM-study (e.g., 19 participants is the median sample size found in prior ESM-studies [28]), it was relatively low for the group-comparisons in this particular study. This may have led to a loss in power to detect group differences. Furthermore, when examining possible reactivity effects, we were not able to compare the responses with a control group. We therefore cannot rule out that changes in PGD levels might have occurred because of the passage of time. Lastly, our sample included only one person who lost a child and most people experienced a natural loss. On average, the

loss occurred 5.5 years earlier and very few people met PGD DSM-5-TR criteria. Our results may therefore not generalize to people who (i) lost their child, (ii) lost a loved one due to traumatic circumstances, experienced a relatively recent loss, or (iii) experience PGD.

In conclusion, this study resulted in the development of ESM-items to assess PGD symptoms in daily life of bereaved people that were deemed suitable by experts. Moment-to-moment assessment of PGD symptom may result in lower symptomatology compared with retrospective recalling of symptoms. However, compliance and retention was challenging. Moreover, according to bereaved people, participating in research examining PGD symptoms in daily life using ESM does not seem harmful and it might even be used as a therapeutic self-monitoring tool.

Acknowledgements

We would like to thank Andreea Pana, Bente Lauxen, Esta Terbrack, Giulia Micheli, Hanneke Bos, Hans van Essen, Laura Urban, Michelle Todorovic, Sophie Becker, and Tom van Die for their support in recruiting participants and collecting the interview-data. We are grateful to the following grief or ESM experts who were willing to participate in the cognitive interviews: Msc. Suzan Soydas, dr. Thomas Vaessen, dr. Jannis Kraiss, dr. Peter ten Klooster, dr. Maarten Eisma.

Role of the funding source

This publication is part of the project ‘Toward personalized bereavement care: Examining individual differences in response to grief treatment’ [ID: Vl.Veni.211G.065] of the research programme [NWO Talent Programme 2021 - Veni] which is financed by the Dutch Research Council (NWO) and awarded to Lonneke I.M. Lenferink.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.comppsy.2022.152351>.

References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Text Revision DSM-5-TR. 5th ed. Amer Psychiatric Pub Inc.; 2022.
- Bakker AB, Demerouti E, Oerlemans W, Sonnentag S. Workaholism and daily recovery: a day reconstruction study of leisure activities. *J Organ Behav* 2013;34(1):87–107. <https://doi.org/10.1002/job.1796>.
- Ben-Zeev D, Young MA. Accuracy of hospitalized depressed patients’ and healthy controls’ retrospective symptom reports: an experience sampling study. *J Nerv Ment Dis* 2010;198(4):280–5. <https://doi.org/10.1097/NMD.0b013e3181d6141f>.
- Boelen PA. Symptoms of prolonged grief disorder as per DSM-5-TR, posttraumatic stress, and depression: latent classes and correlations with anxious and depressive avoidance. *Psychiatry Res* 2021;302. <https://doi.org/10.1016/j.psychres.2021.114033>.
- Boelen PA, Lenferink LIM, Nickerson A, Smid GE. Evaluation of the factor structure, prevalence, and validity of disturbed grief in DSM-5 and ICD-11. *J Affect Disord* 2018;240. <https://doi.org/10.1016/j.jad.2018.04.024>.
- Bos F, Klipstein L, Emerencia AC, Veermans E, Verhage T, Snippe E, et al. Personalized treatment by real-time assessment (PETRA): user-centered development of a web-application for personalized diaries in psychiatric care. *PsyArXiv* 2022. <https://doi.org/10.31234/osf.io/jh49z>.
- Bos FM, Snippe E, Bruggeman R, Wichers M, van der Krieke L. Insights of patients and clinicians on the promise of the experience sampling method for psychiatric care. *Psychiatr Serv* 2019;70(11):983–91. <https://doi.org/10.1176/appi.ps.201900050>.
- Conner TS, Lehman BJ. Getting started: launching a study in daily life. In: *Handbook of research methods for studying daily life*. The Guilford Press; 2012. p. 89–107.
- Degroote L, DeSmet A, De Bourdeaudhuij I, Van Dyck D, Crombez G. Content validity and methodological considerations in ecological momentary assessment studies on physical activity and sedentary behaviour: a systematic review. *Int J Behav Nutr Phys Act* 2020;17(1):35. <https://doi.org/10.1186/s12966-020-00932-9>.
- Heeke C, Franzen M, Hofmann H, Knaevelsrud C, Lenferink LIM. A latent class analysis on symptoms of prolonged grief, post-traumatic stress, and depression following the loss of a loved one. *Front Psych* 2022;13. <https://www.frontiersin.org/article/10.3389/fpsy.2022.878773>.
- Hektner JM, Schmidt JA, Csikszentmihalyi M. Experience sampling method: Measuring the quality of everyday life (pp. xiii, 352). Sage Publications, Inc; 2007.
- Kokou-Kpolou CK, Lenferink LIM, Brunnet AE, Park S, Megalakaki O, Boelen P, et al. The ICD-11 and DSM-5-TR prolonged grief criteria: validation of the traumatic grief inventory-self report plus using exploratory factor analysis and item response theory. *Clin Psychol Psychother* 2022;n/a(n/a). <https://doi.org/10.1002/cpp.2765>.
- Kramer I, Simons CJP, Hartmann JA, Menne-Lothmann C, Viechtbauer W, Peeters F, et al. A therapeutic application of the experience sampling method in the treatment of depression: a randomized controlled trial. *World Psychiatry* 2014;13(1):68–77. <https://doi.org/10.1002/wps.20090>.
- Lenferink LIM, Eisma MC, Smid GE, de Keijser J, Boelen PA. Valid measurement of DSM-5 persistent complex bereavement disorder and DSM-5-TR and ICD-11 prolonged grief disorder: the traumatic grief inventory-self report plus (TGI-SR+). *Compr Psychiatry* 2022;112:152281. <https://doi.org/10.1016/j.comppsy.2021.152281>.
- Lenferink LIM, Franzen M, Boelen PA, Knaevelsrud C, Heeke C. The Traumatic Grief Inventory-Clinician Administered: a psychometric evaluation of a new interview for ICD-11 and DSM-5-TR prolonged grief disorder. <https://dx.doi.org/10.2139/ssrn.4212934>; 2022.
- Lenferink LIM, Keijsers J, Smid GE, Djelantik AAAMJ, Boelen PA. Prolonged grief, depression, and posttraumatic stress in disaster-bereaved individuals: latent class analysis. *Eur J Psychotraumatol* 2017;8(1):1298311. <https://doi.org/10.1080/20008198.2017.1298311>.
- 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. *J Affect Disord* 2017;212:138–49. <https://doi.org/10.1016/j.jad.2017.01.030>.
- Maccallum F, Malgaroli M, Bonanno GA. Networks of loss: relationships among symptoms of prolonged grief following spousal and parental loss. *J Abnorm Psychol* 2017;126(5):652–62. <https://doi.org/10.1037/abn0000287>.
- Myin-Germeys I, Kasanova Z, Vaessen T, Vachon H, Kirtley O, Viechtbauer W, et al. Experience sampling methodology in mental health research: new insights and technical developments. *World Psychiatry* 2018;17(2):123–32. <https://doi.org/10.1002/wps.20513>.
- Newman E, Willard T, Sinclair R, Kaloupek D. Empirically supported ethical research practice: the costs and benefits of research from the participants’ view. *Account Res* 2001;8(4):309–29. <https://doi.org/10.1080/08989620108573983>.
- Nielsen MK, Carlsen AH, Neergaard MA, Bidstrup PE, Guldin M-B. Looking beyond the mean in grief trajectories: a prospective, population-based cohort study. *Soc Sci Med* 2019;232:460–9. <https://doi.org/10.1016/j.socscimed.2018.10.007>.
- Peterson CH, Peterson NA, Powell KG. Cognitive interviewing for item development: validity evidence based on content and response processes. *Meas Eval Counsel Dev* 2017;50(4):217–23. <https://doi.org/10.1080/07481756.2017.1339564>.
- 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 Med* 2009;6(8):1–12. <https://doi.org/10.1371/journal.pmed.1000121>.
- Reis HT. Why researchers should think “real-world”: a conceptual rationale. In: *Handbook of research methods for studying daily life*. The Guilford Press; 2012. p. 3–21.
- Shear MK, Simon N, Wall M, Zisook S, Neimeyer R, Duan N, et al. Complicated grief and related bereavement issues for DSM-5. *Depress Anxiety* 2011;28(2):103–17. <https://doi.org/10.1002/da.20780>.
- Trembl J, Kaiser J, Plexinies A, Kersting A. Assessing prolonged grief disorder: a systematic review of assessment instruments. *J Affect Disord* 2020;274:420–34. <https://doi.org/10.1016/j.jad.2020.05.049>.
- Vachon H, Viechtbauer W, Rintala A, Myin-Germeys I. Compliance and retention with the experience sampling method over the continuum of severe mental disorders: Meta-analysis and recommendations. *J Med Internet Res* 2019;21(12):e14475. <https://doi.org/10.2196/14475>.
- van Berkel N, Ferreira D, Kostakos V. The experience sampling method on mobile devices. *ACM Comput Surv* 2017;50(6). <https://doi.org/10.1145/3123988>. 93: 1–93:40.
- van Os J, Verhagen S, Marsman A, Peeters F, Bak M, Marcelis M, et al. The experience sampling method as an mHealth tool to support self-monitoring, self-insight, and personalized health care in clinical practice. *Depress Anxiety* 2017;34(6):481–93. <https://doi.org/10.1002/da.22647>.
- Verhagen SJW, Hasmi L, Drukker M, van Os J, Delespaul PAEG. Use of the experience sampling method in the context of clinical trials. *Evid Based Ment Health* 2016;19(3):86–9. <https://doi.org/10.1136/ebmental-2016-102418>.
- Walz LC, Nauta MH, aan het Rot, M.. Experience sampling and ecological momentary assessment for studying the daily lives of patients with anxiety disorders: a systematic review. *J Anxiety Disord* 2014;28(8):925–37. <https://doi.org/10.1016/j.janxdis.2014.09.022>.
- Waterman EA, Edwards KM, Dardis CM, Kelley EL, Sessarego S. Assessing intimate partner violence via daily diary surveys: feasibility, reporting, and acceptability. *J Interpers Violence* 2021;36(19–20):9121–42. <https://doi.org/10.1177/0886260519865964>.
- World Health Organization. ICD-11. In: Prolonged grief disorder criteria; 2018. <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1183832314>.