Self-monitoring of prolonged grief disorder (PGD) symptoms: The effect of the experience sampling method (ESM) on PGD-symptoms compared to a waitlist group – a randomized controlled trial (RCT)

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Abstract

Introduction: In 2022, Prolonged Grief Disorder (PGD) was added to the DSM-5-TR. Whereas a PGD can only be diagnosed after twelve months, research has shown that early symptoms can predict clinically significant grief and that grief interventions before the one-year-mark can be effective. One way to possibly tackle grief symptoms could be through self-monitoring of symptoms. Therefore, the goal was to explore whether self-monitoring PGD symptoms through the experience sampling method (ESM) could aid people at risk for PGD (as classified by the DSM-5-TR) in decreasing PGD symptoms compared to a waitlist group. *Methods:* A randomized controlled trial (RCT) was conducted in which treatment-seeking bereaved people who lost a loved one three to six months before study participation were randomly assigned to the ESM or waitlist condition. PGD-symptoms were assessed at T1, T1b and T2 through telephone interviews using items from the Traumatic Grief Inventory-Clinician Administered (TGI-CA). Analysis of covariance (ANCOVA) included PGD at T1b/T2 as dependent variable, condition as independent variable and PGD at T1 as covariate. *Results:* The total sample consisted of 70 participants. Most participants were female (77.1%), lost a partner (54.3%), and lost someone to a physical illness (80.0%). Condition had no significant effect on the severity of PGD-symptoms after waiting/ESM ($F(1, 67) = 0.018$, $p = .895$). Plots depicting individual changes in PGD-severity within the ESM and waitlist condition showed more meaningful increases and decreases in the ESM condition. *Discussion:* To conclude, self-monitoring grief reactions does not seem to have a significant effect on PGD-severity. Future research should focus on samples with clinical PGD, on the addition of therapist assistance and on the reasons behind missing data.

Key words: Prolonged Grief Disorder (PGD), DSM-5-TR, self-monitoring, Experience Sampling Method (ESM), Randomized Controlled Trial (RCT)

One certainty we have in life is that everyone will die someday. Therefore, at some point in our lives, it is likely that we will have to deal with the passing of a loved one. Whereas some of us manage loss well, others do not (Nielsen et al., 2019). A small minority of bereaved individuals of about 7% - 10% experience intense and stable grief symptoms that interfere with daily functioning (Lundorff et al., 2017; Nielsen et al., 2019; Szuhany et al., 2021). Furthermore, such grief symptoms can lead to detrimental health outcomes (Shear, Simon, & Wall, 2011, as cited in Szuhany et al., 2021). Throughout the years, several grief diagnoses with each their own set of grief symptoms have been created (Lenferink et al., 2021). In 2022, the Diagnostic and Statistical manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) made its appearance (American Psychiatric Association, n.d.), which had a new disorder added to their diagnostic manual: Prolonged Grief Disorder (PGD) (American Psychiatric Association, n.d.). Not only is PGD characterized by an extreme longing or preoccupation with a person's late loved one and by the presence of minimally three grief symptoms, the late loved one must have passed away at least twelve months beforehand (Moran, 2020). As PGD-symptoms influence a person's life negatively in present and future, it is of vital importance to alleviate symptoms.

However, the question remains of when to start treatments to alleviate PGD-symptoms. In the Netherlands, mental healthcare treatments are only covered by insurance after an official diagnosis (Kiezen in the ggz, n.d.). Therefore, Dutch citizens can only get PGD-treatments paid by insurance twelve months after the passing of their loved one. However, it might be worthwhile to start PGD-treatments before this twelve-month-mark (Reitsma et al., 2023). Firstly, intense grief symptoms have been shown to predict clinically significant grieving problems in the first few months after the death of a loved one (Boelen & Lenferink, 2022; Bonanno & Malgaroli, 2020; Kristensen et al., 2020; Lenferink et al., 2020a; Nielsen et al., 2019; Sveen et al., 2018; as cited in Reitsma et al., 2023). Secondly,

two interventions to decrease grief symptoms, targeting individuals who lost a loved one less than a year ago, have shown to be effective (Litz et al., 2014; Reitsma et al., 2023). Therefore, it might be beneficial to see what other means could help tackle PGD-symptoms early in the grieving process.

One way to alleviate PGD-symptoms early in the grief process might be through self-monitoring PGD-symptoms. According to Cohen et al. (2013), self-monitoring can be defined as "the systematic observing and recording of target behaviour, such as a client's emotional response, dysfunctional thought, and/or problem behaviour" (p. 419). Self-monitoring symptoms can inspire awareness in someone's behavioural and experiential patterns, which in turn might encourage change (Van Os et al., 2017). Consequently, several studies on self-monitoring symptoms show that self-monitoring might decrease unfavourable mental health symptoms (Kauer et al., 2012; Lenferink et al., 2022b).

One example of such a study is done by Kauer et al. (2012). They studied whether adolescents with early signs of depression who self-monitored their mental strain, mood and everyday tasks experienced an increase in 'emotional self-awareness' and consequently experienced less depressive symptoms. They divided participants into an intervention group (self-monitoring of everyday tasks, mood and mental strain) and an attention comparison group (self-monitoring of everyday tasks). They found that adolescents in the intervention group gained 'emotional self-awareness' which led to less depressive symptoms (Kauer et al., 2012). Thus, self-monitoring of symptoms seems to be valuable for people who are dealing with symptoms of a depression.

However, there might also be a downside to self-monitoring symptoms. For example, Dogan et al. (2017) mention that people with a depressive disorder might notice how they are falling short in their day-to-day lives, which could worsen symptoms (as cited in Folkersma et al., 2021). As self-monitoring depression symptoms might lead to improving or worsening

symptoms, the question remains what self-monitoring symptoms might do for people at risk for PGD.

Although little information is known about self-monitoring PGD-symptoms, one study on this topic has been done. Lenferink et al. (2022b) showed that self-monitoring PGD-symptoms decreased PGD-severity in people who lost a loved one at least three months ago. However, their study did not include a control group. As such, the decrease in PGD-severity could be ascribed to time passing by (Lenferink et al., 2022b). Therefore, a randomized controlled trial (RCT) could have helped with confirming whether the intervention was responsible for a difference in PGD-severity and thus could have provided more evidence for the effect of self-monitoring on PGD-severity (Hariton & Locascio, 2018).

However, the effectiveness of self-monitoring on PGD-severity has not yet been investigated through an RCT. Consequently, this study aims to fill this gap to determine whether people at risk for PGD could benefit from self-monitoring symptoms in an early grief process. To reach this goal, the research question that will be answered is: "To what extent can self-monitoring PGD-symptoms through the experience sampling method (ESM) aid people at risk for PGD (as classified by the DSM-5-TR) in decreasing PGD-severity compared to a waitlist control group?".

Methods

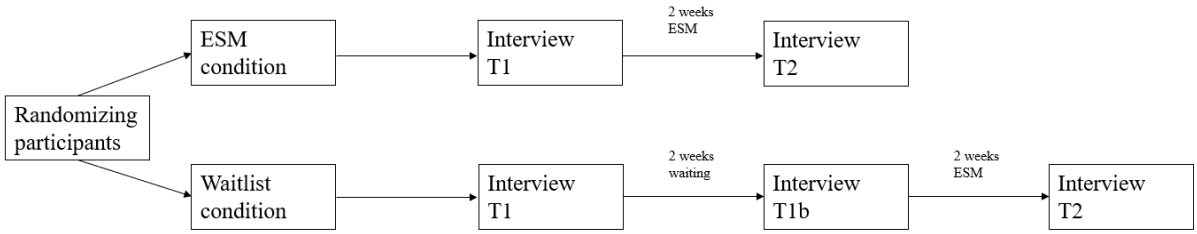
Design

The study's design was a randomized controlled trial (RCT). Participants were gathered through self-selected sampling and they were randomly allocated to the ESM condition (0) or to the waitlist condition (1) through blocking randomisation (random.org). All participants were interviewed at the start of study participation (T1) and at the end of the self-monitoring phase (T2). Participants allocated to the waitlist condition were also

interviewed after two weeks of waiting, just before they started self-monitoring their PGD-symptoms (T1b), as shown in figure 1. The ethical committee for BMS of the University of Twente approved this research (nr. 221328).

Figure 1

Study design: RCT.



Participants

Participants were eligible for study participation when they met all inclusion criteria and none of the exclusion criteria. To be included, participants had to be eighteen years or older, they had to have lost a loved one three to six months before study participation, they had to be fluent in either Dutch or German and they had to have access to a smartphone. Following prior research by Lenferink et al. (2022b) and Reitsma et al. (2023), participants were not allowed to take part in study participation when they were suicidal or when they had been diagnosed with a psychotic disorder. The question regarding suicidality, “Over the past two weeks, how often have you been bothered by thoughts that you would be better off dead, or thoughts of hurting yourself in some way?” (Reitsma et al., 2023, p. 3), was asked at T1, T1b and T2. When participants scored higher than a score of one (“Not at all”), the safety-protocol went into effect to estimate whether it was still safe for a participant to take part in the study (Reitsma et al., 2023). This safety protocol consisted of several questions, such as “Over the past four weeks, have you considered ending your life?” (Reitsma et al., 2023, p.

3). Suicidal participants were given advice and were told where they could look for help. Furthermore, suicidal participants were not allowed to continue study participation. People were screened for a psychotic disorder at T1 through the question “Have you ever received a diagnosis for a psychotic disorder from a psychologist, therapist or psychiatrist?”.

Participants were recruited through a Dutch grief website (rouwbehandeling.nl). On this website, participants were able to find information regarding grief, care and they were able to find a self-monitoring tool (“grief monitor”) for grief symptoms (Lenferink & Boelen, 2023a). Once people filled in the self-monitoring tool, they were asked whether they wanted to participate in future research about grief (Lenferink et al., 2023a). People who responded “Yes” were contacted by a student from the University of Twente or the Erasmus University via e-mail once the possible participant’s loved one passed away three to six months earlier. Participants were recruited from February 2023 until April 2023.

Procedure

People meeting the inclusion criteria were sent a standardized invitation e-mail to participate in the study. In this standardized e-mail, they found a link which led them to Qualtrics (https://www.qualtrics.com/nl/). This link contained an information letter including an informed consent form (Lenferink et al., 2022b). If a person agreed to participate, they became a participant: (1) they got an ID-number and (2) they got randomly assigned to either the ESM or the waitlist condition. Furthermore, they received a phone call to schedule the first interview (T1) (Lenferink et al., 2022b). If people did not fill in the informed consent after one week, they received a reminder invitation e-mail to participate in the study.

Participants who had scheduled T1 received a reminder e-mail regarding their telephone-based interview one to two days beforehand. Following this e-mail, T1 took place at the agreed time. Interviews were held by clinical psychology master students who followed

a training on how to do the T1, T1b and T2 interviews. In this training, they were given information by their supervisors and they practised with the interviews. After the first interview, participants were asked to plan a new interview appointment together with the researcher. This second interview took place within one week after the ESM-phase or the waiting period.

Participants who were assigned to the control condition were asked to wait for two weeks until their next telephone-based interview, whereas participants who were assigned to the ESM condition immediately started with self-monitoring via the Ethica app (https://ethicadata.com/) (Lenferink et al., 2022b); these participants received an instruction e-mail after the interview in which it was explained how to install the app and how to sign up for the study (Lenferink et al., 2022b). Participants got five notifications per day for a period of two weeks in which they were asked to answer ESM questions regarding their PGD-symptoms (Lenferink et al., 2022b). Time between notifications was three hours, where the first notification arrived between 08.30h and 09.30h and the last notification arrived between 20.30h and 21.30h (Lenferink et al., 2022b). Participants received reminder e-mails when they did not fill in the ESM-items (Lenferink et al., 2022b).

Following the first interview, the T1tb/T2 interview took place 14 to 21 days after the T1 interview, which participants were reminded of one to two days beforehand. This was T2 for the ESM condition and T1b for the waitlist condition (Figure 1). Whereas participants in the ESM condition were done with study participation after T2, participants from the waitlist condition still went through the self-monitoring phase, after which they had their T2 interview and subsequently ended study participation.

Measures

Measures included an interview-questionnaire and an ESM-questionnaire. For the interview-questionnaire, several questionnaires were adopted, such as the Traumatic Grief Inventory-Clinician Administered (TGI-CA), the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5) and the Patient Health Questionnaire (PHQ-9). As this study focused on grief, only the TGI-CA and the questions regarding background and loss-related characteristics were discussed in depth. The TGI-CA was present in T1, T1b and T2, whereas questions regarding background and loss-related characteristics were only present in T1. Lastly, the ESM-questionnaire to self-monitor PGD-symptoms was discussed more in depth.

PGD-symptoms (TGI-CA)

To assess PGD-severity, the Traumatic Grief Inventory-Clinician Administered (TGI-CA) was used. The TGI-CA is a 22-item questionnaire measuring PGD-symptoms as described by the DSM-5-TR and the ICD-11 through an interview format (Lenferink et al., 2022, as cited in Lenferink et al., 2023b). Reliability and validity of the TGI-CA are presumably worthwhile to evaluate PGD-severity (Lenferink et al., 2023b). Items found in the supplemental material from Lenferink et al. (2023b), such as "in the past month, did you find it hard to trust others?" (p. 1), were adapted so that they would fit the two-week period between interviews (Lenferink et al., 2023b). These items were measured on a scale from one to five, where one stood for "Never" and five stood for "Always" (Lenferink et al., 2023b). Participants who had a total sum score of ≥71 were seen as probable of meeting clinically significant PGD-criteria (Lenferink et al., 2022a). Cronbach's alpha at baseline was .87.

Background and Loss-related Characteristics

Next to PGD-severity, background and loss-related items were measured at T1. Questions were asked regarding background characteristics (gender, age, home country and

level of education) and loss characteristics (age of death, time since loss, kinship, cause of death, expectancy of death, mental support and PGD at baseline) (Lenferink et al., 2022b). Several items had predefined answer options, such as kinship (1 = partner, 2 = child, 3 = mom/dad, 4 = brother/sister, 5 = grandfather/grandmother, 6 = grandchild, 7 = friend, 8 = none of the above, namely…), whereas other items were open questions, such as home country.

ESM-questions

Questions were taken from Lenferink et al. (2022b), who formulated ESM-questions to assess PGD-severity several times per day. They took items that fit DSM-5-TR criteria for PGD (American Psychiatric Association, 2022, as cited in Lenferink et al., 2022b) from the Traumatic Grief Inventory – Self Report Plus (TGI-SR+) (Lenferink et al., 2022, as cited in Lenferink et al., 2022b). These items were adapted to fit the ESM timeframe (Lenferink et al., 2022b). Expert interviews led to small adaptations to these items, which in turn aided validity (Lenferink et al., 2022b). An example of an item used for ESM is “In the past three hours, I found myself yearning for him/her.” (Lenferink et al., 2022b, p. 5). There were 11 PGD-items in total which ranged from “not at all” (0) to “very much” (6) (Lenferink et al., 2022b). Furthermore, there were six questions regarding context (Lenferink et al., 2022b).

Data analyses

To answer the research question “To what extent can self-monitoring PGD-symptoms through ESM aid people at risk for PGD (as classified by the DSM-5-TR) in decreasing their symptoms compared to a waitlist control group?”, data were analysed using SPSS 28. Before starting analyses, data were cleaned by removing participants who filled in less than 50% of the ESM-items (Conner & Lehman, 2012, as cited in Lenferink et al., 2022b). Afterwards,

total scores for the TGI-CA at T1 and T1b/T2 were created by summing all answers per participant (Lenferink et al., 2022b), age was computed from T1's start date and the participant's birth date and time since loss was computed from T1's start date and date of death. Furthermore, a new kinship variable (0 = Partner/child, 1 = other) and a new cause of death variable (0 = physical illness, 1 = other) were created as shown in prior research by Reitsma et al. (2023).

First, background and loss-characteristics were analysed. For age of the participant, age of the deceased, time since loss and symptom-levels PGD at T1, means and standard deviations were calculated. For the other variables, number of participants and percentages were calculated. For the whole sample, a line graph and boxplot were shown to visualize means, standard deviations and distributions. Per condition, a line graph and two boxplots were shown visualizing means, standard deviations and distributions. Furthermore, group differences at baseline were measured using independent sample t-tests for "age" and "symptom-levels PGD at T1", and chi square tests were used for measuring "cause of death", "kinship", "education" and "gender" (Reitsma et al., 2023).

Secondly, an Analysis of Covariance (ANCOVA) was performed to answer the research question. Following prior research (Reitsma et al., 2023), PGD levels at T1b/T2 were included as dependent variable, PGD levels at T1 as covariate, and group allocation (0 = ESM and 1 = waitlist) as independent variable. Furthermore, plots were made to show individual differences for PGD-severity between T1 and T1b/T2 for both groups. For both groups it was chosen to have a difference of 1 SD (ESM $\geq$ 13, waitlist $\geq$ 15) as a meaningful difference. Meaningful decreases in PGD-severity were coloured green, meaningful increases were coloured red and no meaningful differences were coloured orange.

Results

Background and Loss Characteristics

The participant flow can be seen in Figure 2. People who agreed to the consent form were invited for the T1 interview (N = 74). These participants were randomly allocated to either the waitlist condition (N = 42) or to the ESM condition (N = 32). Four participants were excluded from the ESM condition, because they did not fill in 50% or more of the ESM-items (< 35). After this exclusion, the total sample was established (N = 70; ESM condition = 28, Waitlist condition = 42).

Age of participants ranged from 25.2 to 84.7 (M = 55.9, SD = 12.6). Most participants were female (77.1%), were from the Netherlands (92.9%) and most participants had a university/college degree (61.4%). Age of deceased loved ones ranged from 0 – 90 (M = 62.0 SD = 19.7). Most loved ones were a participant's partner (54.3%) and passed away due to a physical illness (80.0%). At T1, 32.9% of participants received mental support due to the passing of their loved one. For all other demographics, see Table 1. Furthermore, Figure 3 and Figure 4 show means, standard deviations and distributions of PGD-severity at T1 and T1b/T2 for both groups combined. Figure 5 and Figure 6 show means, standard deviations and distributions of PGD-severity at T1 and T1b/T2 for both groups separately. For participants in the ESM-condition, 4 (14.3%) met criteria for probable PGD at T1 and 3 (10.7%) at T2. For participants in the waitlist condition, 4 (9.5%) met criteria for probable PGD at T1 and 7 (16.7%) at T2. There were no significant background and loss-related differences between groups at baseline (Table 2).

Figure 2

Participant flow.

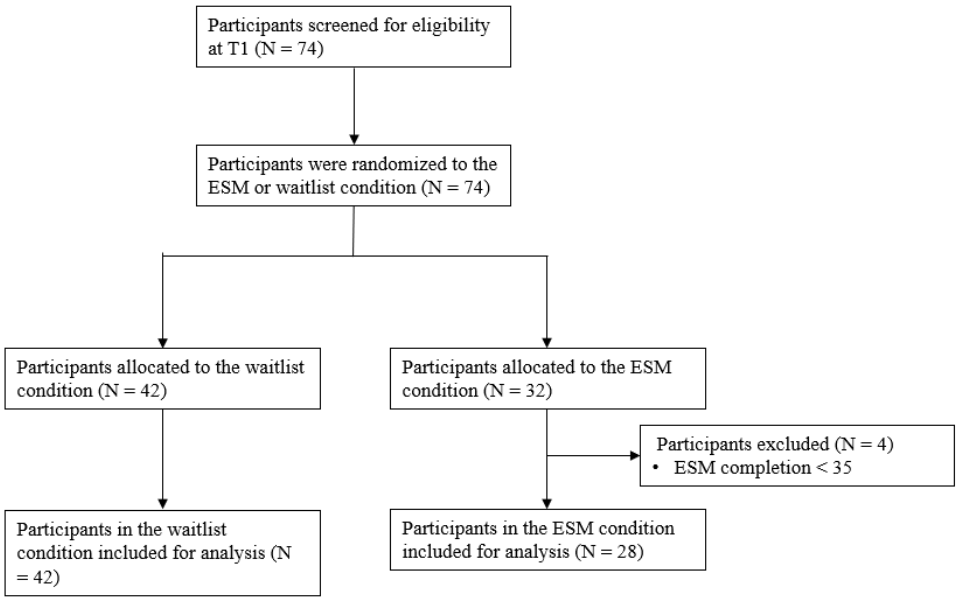


Table 1

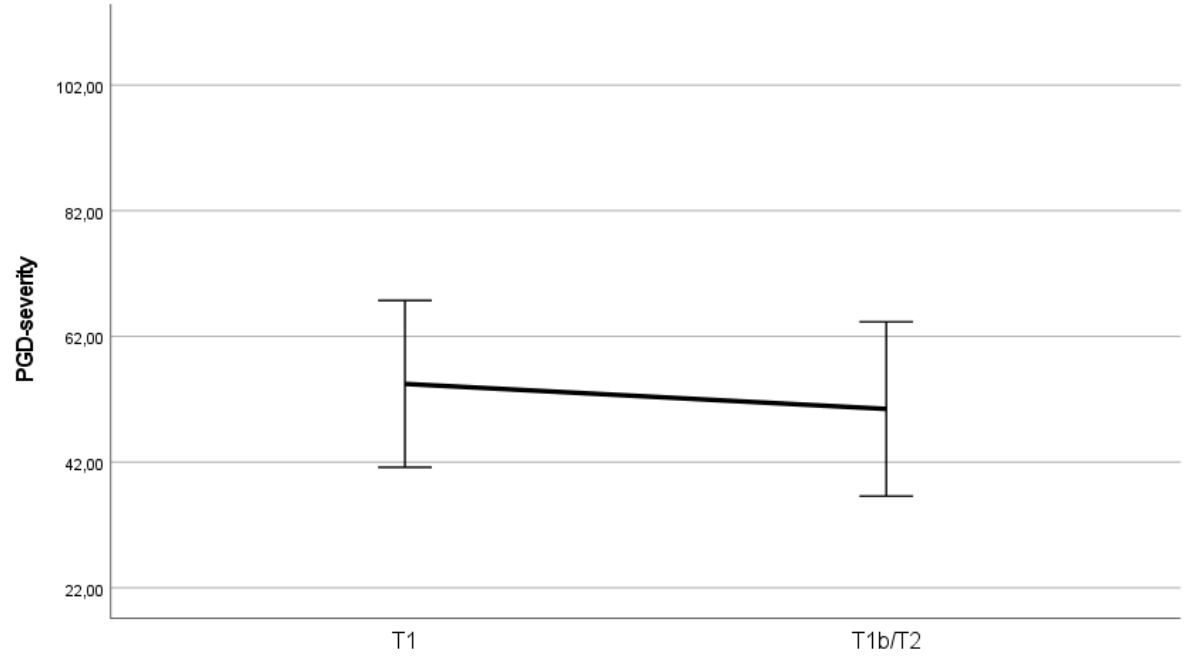
Background, loss-related characteristics and PGD-levels at baseline in the whole sample and per condition.

Characteristic	**Total sample**		**ESM condition (N = 28)**		**Waitlist condition (N = 42)**	
Gender, *N* (%)						
Female	54	(77.1)	21	(75.0)	33	(78.6)
Man	16	(22.9)	7	(25.0)	9	(21.4)
Other	0	(0.0)	0	(0.0)	0	(0.0)
Age (in years), *M* (SD)	55.9	(12.6)	57.0	(12.5)	55.2	(12.8)
Home country, *N* (%)						
The Netherlands	65	(92.9)	27	(96.4)	38	(90.5)
Germany	3	(4.3)	1	(3.6)	2	(4.8)
Belgium	1	(1.4)	0	(0.0)	1	(2.4)
Algeria	1	(1.4)	0	(0.0)	1	(2.4)
Education, *N* (%)						
Primary school	0	(0.0)	0	(0.0)	0	(0.0)
High school	7	(10.0)	3	(10.7)	4	(9.5)
Vocational education	20	(28.6)	9	(32.1)	11	(26.2)
College/University	43	(61.4)	16	(57.1)	27	(64.3)
Kinship, *N* (%)						
Partner	38	(54.3)	17	(60.7)	21	(50.0)
Child	5	(7.1)	1	(3.6)	4	(9.5)
Parent	20	(28.6)	8	(28.6)	12	(28.6)
Sibling	1	(1.4)	1	(3.6)	0	(0.0)

Grandparent	0	(0.0)	0	(0.0)	0	(0.0)
Grandchild	1	(1.4)	0	(0.0)	1	(2.4)
Friend	2	(2.9)	0	(0.0)	2	(4.8)
Other	3	(4.3)	1	(3.6)	2	(4.8)
Age of the deceased (in years), *M* (SD)	62.0	(19.6)	64.6	(13.9)	60.2	(22.7)
Cause of death, *N* (%)						
Physical illness	56	(80.0)	23	(82.1)	33	(78.6)
Accident	2	(2.9)	2	(7.1)	0	(0.0)
Suicide	5	(7.1)	1	(3.6)	4	(9.5)
Murder/manslaughter	0	(0.0)	0	(0.0)	0	(0.0)
Other	7	(10.0)	2	(7.1)	5	(11.9)
Expectancy of death, *N* (%)						
Not at all unexpected	15	(21.4)	4	(14.3)	11	(26.2)
A little unexpected	13	(18.6)	8	(28.6)	5	(11.9)
Quite unexpected	8	(11.4)	4	(14.3)	4	(9.5)
Very unexpected	11	(15.7)	3	(10.7)	8	(19.0)
Fully unexpected	23	(32.9)	9	(32.1)	14	(33.3)
Time since loss (in days), *M* (SD)	160.5	(33.7)	161.3	(34.0)	159.9	(33.8)
Mental support – unrelated to loss, *N* (%)						
Yes	38	(54.3)	14	(50.0)	24	(57.1)
No	32	(45.7)	14	(50.0)	18	(42.9)
Mental support – grief support, *N* (%)						
Yes	28	(40.0)	13	(46.4)	15	(35.7)
No	42	(60.0)	15	(53.6)	27	(64.3)
Mental support – Current grief support, *N* (%)						
Yes	23	(32.9)	11	(39.3)	12	(28.6)
No	5	(7.1)	2	(7.1)	3	(7.)
Symptom-levels PGD at T1, *M* (SD)	54.5	(13.3)	55.9	(12.3)	53.5	(14.0)

Figure 3

Line graph depicting means and standard deviations of PGD-severity at T1 and T1b/T2.



Note. The bars show ± 1 SD from the mean.

Figure 4

Boxplot depicting distributions in PGD-severity at T1 and T1b/T2.

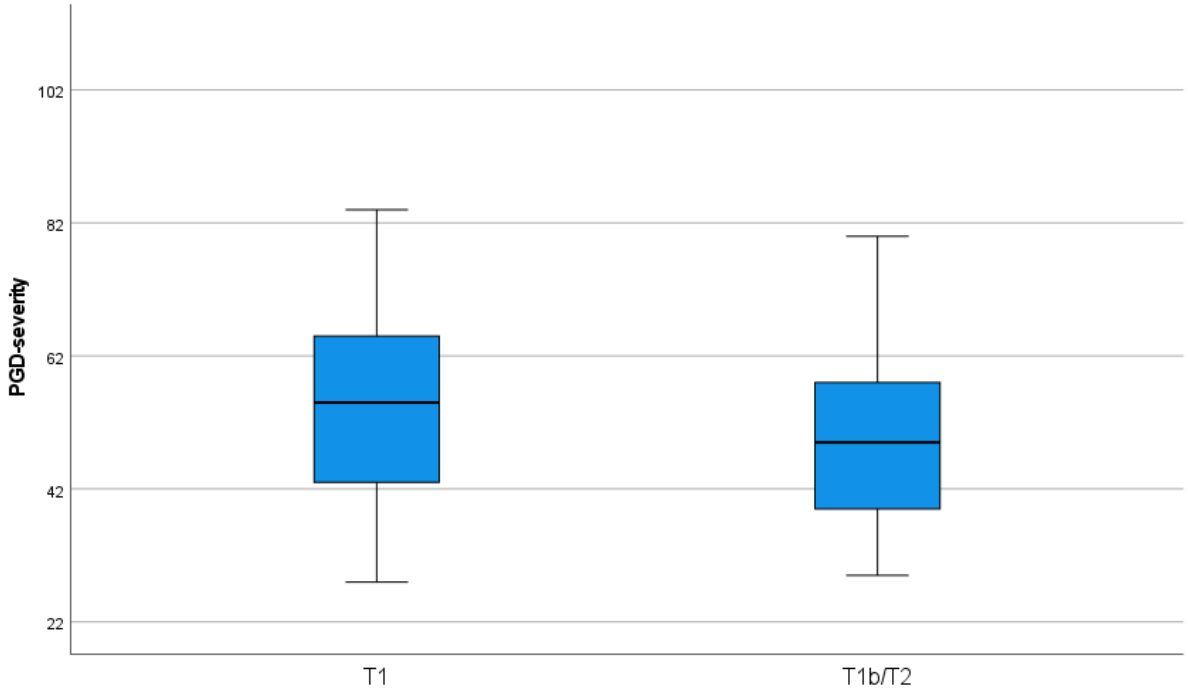
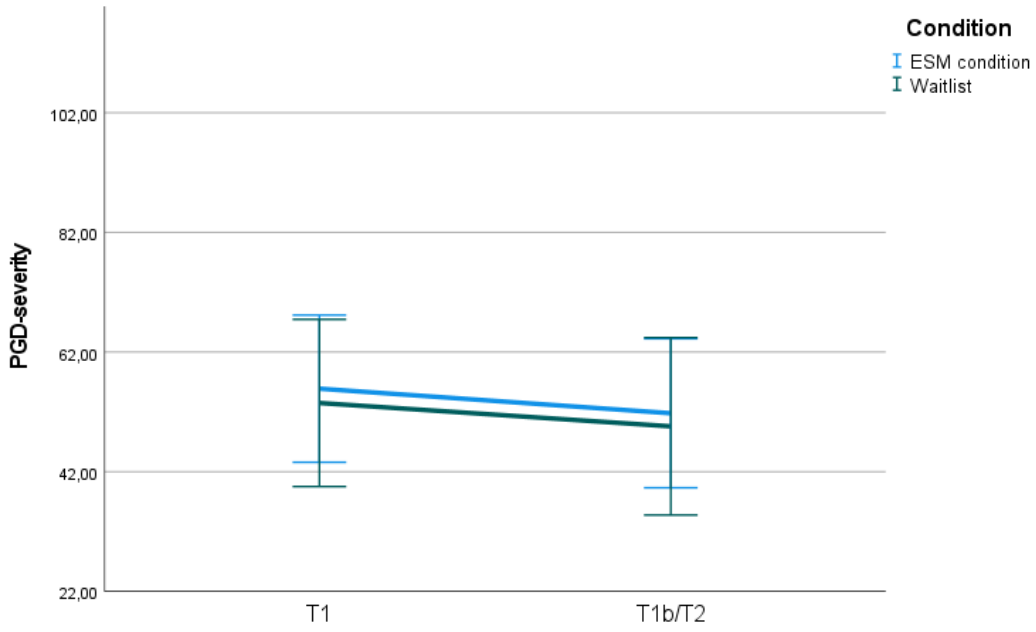


Figure 5

Means and standard deviations at T1 and T1b/T2 per condition.



Note. The bars show ± 1 SD from the mean.

Figure 6

Distributions at T1 and T1b/T2 per condition.

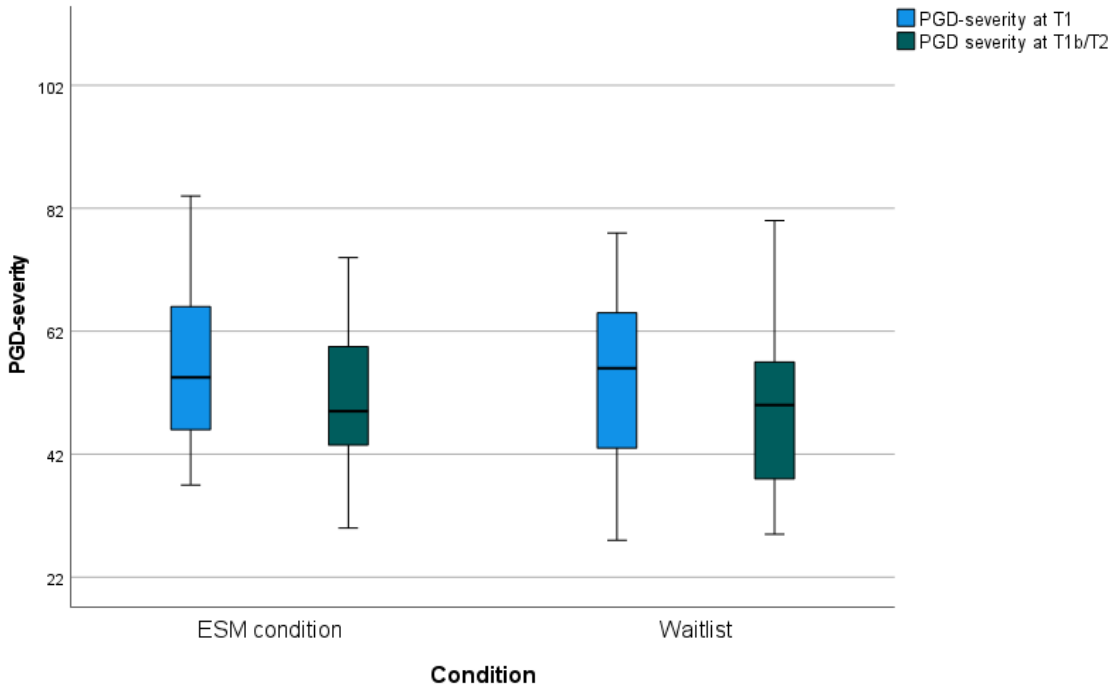


Table 2

Baseline differences between groups.

Characteristic	Test	df	p-value
Gender	$\chi^2 = .112$	1	.727
Age	t = .590	68	.557
Education	$\chi^2 = .372$	2	.830
Kinship	$\chi^2 = .161$	1	.688
Cause of death	$\chi^2 = 0.134$	1	.714
Symptom-levels			
PGD at T1	t = .736	68	.464

Note. Kinship was made into a dichotomy (0 = Partner/child, 1 = other) and cause of death was made into a dichotomy (0 = physical illness, 1 = other) as shown in prior research by Reitsma et al. (2023).

Changes in PGD symptoms from baseline to post-waiting/post-treatment

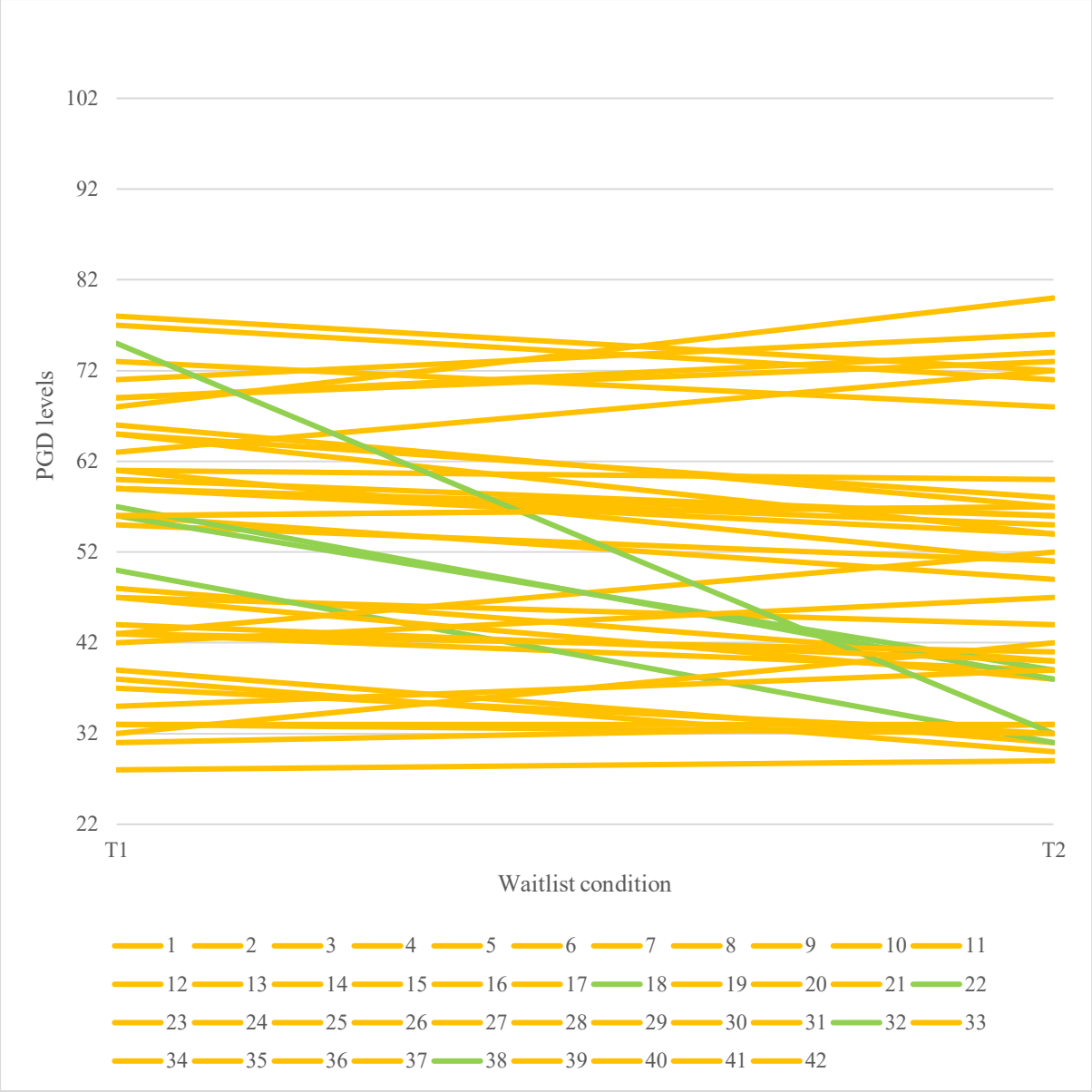
An ANCOVA indicated that there was no significant effect of self-monitoring PGD-symptoms on PGD-severity between the waitlist condition (M=49.6, SD = 14.8) and the ESM condition (M = 51.8, SD = 12.4) from baseline scores ($F(1, 67) = 0.018$, $p = .895$).

Individual Differences in PGD-severity Between Groups

Plots of individual differences showed that 38 participants in the waitlist condition neither improved or worsened in PGD-severity (90.5%), that 4 participants in the waitlist condition improved in PGD-severity (9.5%) and that 0 participants in the waitlist condition worsened in PGD-severity (0.0%) (Figure 7). Furthermore, plots of individual differences showed that 22 participants in the ESM condition neither improved or worsened in PGD-severity (78.6%), that 5 participants in the ESM condition improved in PGD-severity (17.9%) and that 1 participant in the ESM condition worsened in PGD-severity (3.6%) (Figure 8).

Figure 7

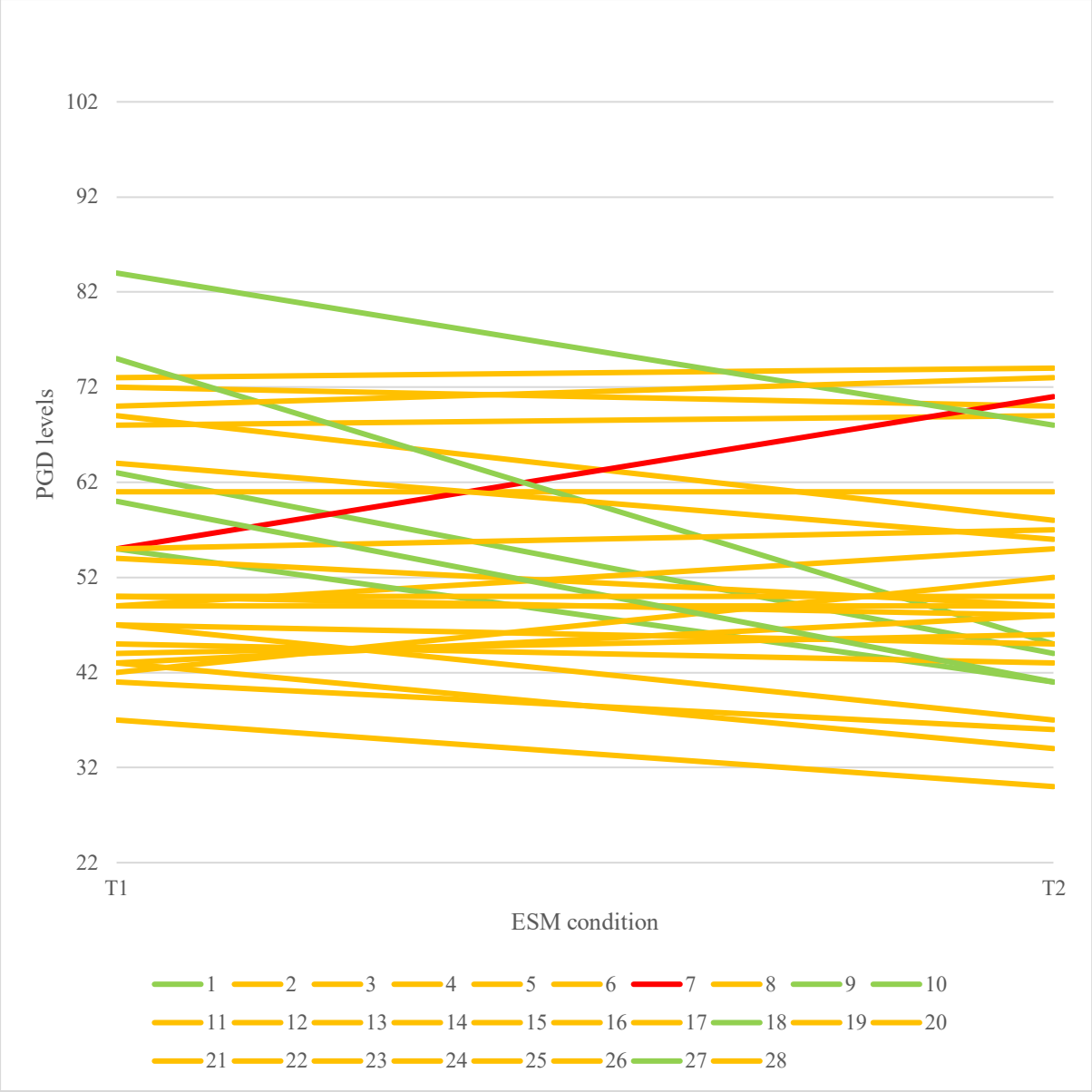
Individual differences between baseline PGD-symptoms and PGD-symptoms after waiting in the waitlist condition (N=42).



Note. In this figure, it was chosen to have differences of ≥15 as a meaningful difference, since this was one standard deviation. Meaningful decreases were coloured green and no meaningful differences were coloured orange.

Figure 8

Individual differences between baseline PGD-symptoms and PGD-symptoms after self-monitoring in the ESM condition (N=28).



Note. In this figure, it was chosen to have differences of ≥13 as a meaningful difference, since this was one standard deviation. Meaningful increases in PGD-severity were coloured red, meaningful decreases were coloured green and no meaningful differences were coloured orange.

Discussion

The effect of self-monitoring PGD-symptoms was assessed in comparison with a waitlist condition through bi-weekly interviews. Whereas PGD can only be diagnosed after twelve

months, there is evidence that treating symptoms before the twelve-month-mark might be fruitful (Litz et al., 2014; Reitsma et al., 2023). Self-monitoring PGD-symptoms was identified as one possibility to tackle symptoms earlier in the grieving process. Though several studies have shown that self-monitoring complaint-related symptoms might be beneficial (Kauer et al., 2012; Lenferink et al., 2022b), some concerns have been raised regarding the self-monitoring of symptoms (Dogan et al., 2017, as cited in Folkersma et al., 2021). Therefore, the aim of this study was to determine whether people at risk for PGD could benefit from self-monitoring PGD-symptoms earlier in the grieving process compared to a waitlist control group.

Findings suggest that self-monitoring PGD-symptoms does not have a significant effect on PGD-severity in comparison to a waitlist control group. Individual plots depicting changes in PGD-severity, however, did show some meaningful decreases in PGD-severity in both the ESM (17.9%) and waitlist (9.5%) condition and some meaningful increases in PGD-severity in the ESM condition (3.6%). Notable is that PGD-severity only increased in the ESM-condition. This could possibly be ascribed to time passing by (Lenferink et al., 2022b), but also to possible downsides of tracking one's own symptoms (Dogan et al., 2017, as cited in Folkersma et al., 2021). Furthermore, as only four (14.3%) participants in the ESM condition met probable PGD-criteria at T1, generalizability of results is limited. Lastly, this seems to be one of the first studies available on self-monitoring PGD-symptoms, where meta-analyses on the topic do not seem to exist. As there is yet so little information available on self-monitoring PGD-symptoms, as results cannot be generalized to a clinical PGD-sample and as it remains unclear why the only participant that increased in PGD-severity was in the ESM condition, future research should remain careful when investigating the effects of self-monitoring in a sample with participants exhibiting PGD-symptoms, especially in a sample in which all participants meet the cut-off score for probable PGD.

The use of a non-clinical sample might explain why no significant effects of self-monitoring PGD-symptoms were found on PGD-severity. As most people come to terms with the passing of their loved one in the first couple of months after their death, they start to regain the ability to live a life they consider worthwhile (Zisook & Shear, 2009). Although people still experience some symptoms, they are often not as debilitating as they were in the beginning (Zisook et al., 2009). Most participants scored below the cut-off for probable PGD at T1, which might indicate that most participants were in a normal grieving stage in which self-monitoring could not reach its desired effect, as intense grief symptoms in the first few months have shown to predict clinically relevant grieving problems (Boelen & Lenferink, 2022; Bonanno & Malgaroli, 2020; Kristensen et al., 2020; Lenferink et al., 2020a; Nielsen et al., 2019; Sveen et al., 2018; as cited in Reitsma et al., 2023). Therefore, participants with clinical levels of PGD, who thus experienced more symptoms and were not in a normal grieving stage, might have been able to gain better treatment outcomes.

That more symptoms could benefit treatment outcome has been shown in people with a depressive disorder. Driessen et al. (2010) showed in their meta-analysis that higher levels of depression before treatment led to better treatment outcomes than low levels of depression. Notable is that the two highest scoring participants in the ESM-condition, who met the cut-off for probable PGD, had significant decreases in PGD-severity. Therefore, clinical PGD samples might yield better treatment outcomes and future research should thus focus on self-monitoring PGD-symptoms in clinical PGD samples.

Another possible reason why no significant effects were found for self-monitoring PGD-symptoms on PGD-severity compared to a waitlist control group might have been due to the lack of therapist assistance. Kramer et al. (2014) showed in an RCT-study that individually tailored feedback in combination with an ESM-intervention on positive affect decreased symptoms of depression. What they found was that participants who got feedback

tried to incorporate what they learned in daily life (Kramer et al., 2014). The reasoning for the effectiveness of the intervention in combination with the feedback was that participants (1) experienced an increase in awareness and (2) that they adapted their way of doing things (Kramer et al., 2014). As participants in this study did not get feedback, it could have been that (1) participants did not experience enough awareness in PGD symptomatology to change their ways and/or (2) that participants were unsure what to do to decrease PGD-severity once they became more aware of their symptoms. Therefore, future research should focus on adding individually tailored feedback to self-monitoring PGD-symptoms.

There are several noteworthy strengths to this study. The first one is that individual changes in PGD-severity were visualized and analysed between groups next to calculating an ANCOVA, means and standard deviations per group. Due to both visualizations, it became clear that there were some significant changes in PGD-severity in both groups. This positively contributed to interpreting results and giving recommendations for future research. A second strength is the use of a RCT-design. As mentioned before, a study done by Lenferink et al. (2022b) showed that self-monitoring PGD symptoms could be helpful, but could not guarantee this due to the lack of a control group. As the current study did make use of a control group, results gave more insight into the effect of time and self-monitoring PGD-symptoms on PGD-severity. Finally, a third strength was the use of ‘grief monitor’ on rouwbehandeling.nl to gather participants. People who used the self-monitoring tool ‘grief monitor’ were often already looking for grief care (rouwbehandeling, n.d.). Furthermore, using a self-selected sample can contribute to finding motivated participants (Laerd dissertation, n.d.). Therefore, using this sample could have led to more motivated participants who were willing to get more insight into their grief and who were willing to contribute to possible new options in grief care.

However, this study also has some noteworthy limitations. A first limitation is that a large majority of participants did not meet the diagnostic criteria for a PGD-diagnosis. As participants seemed to experience normal levels of complaints, it is difficult to conclude whether people at risk for PGD benefit from self-monitoring their symptoms. Therefore, results cannot be extrapolated to people who would seem to be at risk for PGD (Lenferink et al., 2022b). A second limitation is the supportive message participants received when they did not fill in the self-monitoring items (Reitsma et al., 2023). Whereas sending an e-mail to motivate participants might have helped them stick to self-monitoring PGD-symptoms, such assistance would not quickly be available in real-life. A third limitation is that there is no information available as to why participants missed self-monitoring moments. For example, participants could have chosen to skip filling in ESM-items on days they were feeling particularly sad about the passing of their loved one (Gunthert & Wenze, 2012). Consequently, participants would have missed moments in which self-monitoring might have given a lot of insights into their symptoms, which could explain why there were so little decreases in PGD-severity. However, this is only speculation, since it cannot be backed up by any of the results. Not knowing why participants missed ESM-items leaves out important information (Scollon et al., 2003, as cited in Gunthert et al., 2012). Therefore, future research should look at the reasons behind missing data.

All in all, it seems that self-monitoring PGD-symptoms had no significant effect on PGD-severity in comparison to a waitlist control group, although meaningful differences were detected in both conditions. Several reasons could explain these findings, such as the lack of participants meeting the cut-off for probable PGD and the lack of therapist assistance. Furthermore, this study had several strengths, such as the study design, but also some limitations, such as the lack of information on missing data. More research needs to be done on self-monitoring PGD-symptoms. Future research should focus on (1) the effectiveness of

self-monitoring PGD-symptoms in a clinical setting, on (2) the addition of individually-tailored feedback to self-monitoring PGD-symptoms and on (3) the reasons behind missing data.

Reference list

American Psychiatric Association (n.d.). *About DSM-5-TR*. https://www.psychiatry.org/psychiatrists/practice/dsm/about-dsm

American Psychiatric Association (n.d.). *Prolonged Grief Disorder*. https://www.psychiatry.org/patients-families/prolonged-grief-disorder#:~:text=Marked%20sense%20of%20disbelief%20about,%2C%20planning%20for%20the%20future

Cohen, J. S., Edmunds, J. M., Brodman, D. M., Benjamin, C. L., & Kendall, P. C. (2013). Using self-monitoring: Implementation of collaborative empiricism in cognitive-behavioral therapy. *Cognitive and Behavioral Practice, 20*(4), 419-428. doi:10.1016/j.cbpra.2012.06.002

Driessen, E., Cuijpers, P., Hollon, S. D., & Dekker, J. J. (2010). Does pretreatment severity moderate the efficacy of psychological treatment of adult outpatient depression? A meta-analysis. *Journal of consulting and clinical psychology, 78*(5), 668. doi:10.1037/a0020570

Folkersma, W., Veerman, V., Ornée, D. A., Oldehinkel, A. J., Alma, M. A., & Bastiaansen, J. A. (2021). Patients' experience of an ecological momentary intervention involving self-monitoring and personalized feedback for depression. *Internet Interventions, 26*, 100436. doi: 10.1016/j.invent.2021.100436

Gunthert, K.C., & Wenze, S.J. (2012). Daily Dairy Methods. In Mehl, M. R., & Conner, T. S. *Handbook of research methods for studying daily life* (pp. 144-159). Guilford Press.

https://web-p-ebscohost com.ezproxy2.utwente.nl/ehost/ebookviewer/ebook?sid=a91ea42d-8815-4de9-8826-413959152f58%40redis&ppid=pp_i&vid=0&format=EB

Hariton, E., & Locascio, J. J. (2018). Randomised controlled trials—the gold standard for effectiveness research. *BJOG: an international journal of obstetrics and gynaecology, 125*(13), 1716. doi:10.1111/1471-0528.15199

Kauer, S. D., Reid, S. C., Crooke, A. H. D., Khor, A., Hearps, S. J. C., Jorm, A. F., ... & Patton, G. (2012). Self-monitoring using mobile phones in the early stages of adolescent depression: randomized controlled trial. *Journal of medical Internet research, 14*(3), 1-17. doi:10.2196/jmir.1858

Kiezen in de ggz. (n.d*.). Hoe werkt de ggz?* https://kiezenindeggz.nl/hoe-werkt-de-ggz

Kramer, I., Simons, C. J., Hartmann, J. A., Menne‐Lothmann, C., Viechtbauer, W., Peeters, F., ... & Wichers, M. (2014). A therapeutic application of the experience sampling method in the treatment of depression: a randomized controlled trial. *World Psychiatry, 13*(1), 68-77. doi:10.1002/wps.20090

Laerd dissertation. (n.d.). *Self-selection sampling*. https://dissertation.laerd.com/self-selection-sampling.php

Lenferink, L. I. M., Boelen, P. A., Smid, G. E., & Paap, M. C. S. (2021). The importance of harmonising diagnostic criteria sets for pathological grief. *The British Journal of Psychiatry, 219*(3), 473-476. doi:10.1192/bjp.2019.240

Lenferink, L. I. M., & Boelen, P. A. (2023a). DSM-5-TR prolonged grief disorder levels after natural, COVID-19, and unnatural loss during the COVID-19 pandemic. *Journal of Affective Disorders Reports, 12*, 100516. doi:10.1016/j.jadr.2023.100516

Lenferink, L. I., Eisma, M. C., Smid, G. E., de Keijser, J., & Boelen, P. A. (2022a). 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+). *Comprehensive psychiatry, 112*, 152281. doi:10.1016/j.comppsych.2021.152281

Lenferink, L. I. M., van Eersel, J. H. W., & Franzen, M. (2022b). Is it acceptable and feasible to measure prolonged grief disorder symptoms in daily life using experience sampling methodology? *Comprehensive psychiatry, 199*, 1-8. doi:10.1016/j.comppsych.2022.152351

Lenferink, L. I., Franzen, M., Ten Klooster, P. M., Knaevelsrud, C., Boelen, P. A., & Heeke, C. (2023b). The Traumatic Grief Inventory-Clinician Administered: A psychometric evaluation of a new interview for ICD-11 and DSM-5-TR prolonged grief disorder severity and probable caseness. *Journal of Affective Disorders, 330*, 188-197. doi:10.1016/j.jad.2023.03.006

Litz, B. T., Schorr, Y., Delaney, E., Au, T., Papa, A., Fox, A. B., ... & Prigerson, H. G. (2014). A randomized controlled trial of an internet-based therapist-assisted indicated preventive intervention for prolonged grief disorder. *Behaviour research and therapy, 61*, 23-34. doi:10.1016/j.brat.2014.07.005

Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I., & O'Connor, M. (2017). Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. *Journal of affective disorders, 212*, 138-149. doi:10.1016/j.jad.2017.01.030

Moran, M. (2020, October 28). *Board Approves New prolonged Grief Disorder for DSM*. https://psychnews.psychiatryonline.org/doi/10.1176/appi.pn.2020.11a12

Nielsen, M. K., Carlsen, A. H., Neergaard, M. A., Bidstrup, P. E., & Guldin, M. B. (2019). Looking beyond the mean in grief trajectories: A prospective, population-based

cohort study. *Social Science & Medicine, 232*, 460-469. doi:10.1016/j.socscimed.2018.10.007

Reitsma, L., Boelen, P. A., de Keijser, J., & Lenferink, L. I. M. (2023). Self-guided online treatment of disturbed grief, posttraumatic stress, and depression in adults bereaved during the COVID-19 pandemic: A randomized controlled trial. *Behaviour research and therapy, 163*, 104286. doi:10.1016/j.brat.2023.104286

Rouwbehandeling. (n.d.). *Rouwmeter*. https://rouwbehandeling.nl/rouwmeter/

Szuhany, K. L., Malgaroli, M., Miron, C. D., & Simon, N. M. (2021). Prolonged Grief Disorder: Course, Diagnosis, Assessment, and Treatment. *Focus (American Psychiatric Publishing), 19*(2), 161–172. doi:10.1176/appi.focus.20200052

van Os, J., Verhagen, S., Marsman, A., Peeters, F., Bak, M., Marcelis, M., ... & Delespaul, P. (2017). The experience sampling method as an mHealth tool to support self‐monitoring, self‐insight, and personalized health care in clinical practice. *Depression and anxiety, 34*(6), 481-493. doi:10.1002/da.22647

Zisook, S., & Shear, K. (2009). Grief and bereavement: what psychiatrists need to know. *World psychiatry, 8*(2), 67. doi:10.1002/j.2051-5545.2009.tb00217.x