Self-monitoring Prolonged Grief Symptoms in daily life using Experience Sampling Methodology

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Abstract

Introduction: Most bereaved individuals find ways to cope with their loss, allowing them to move forward, while others experience intense, enduring grief that severely impairs daily life, known as Prolonged Grief Disorder (PGD). Prior research suggests self-monitoring as a promising tool for improving PGD symptoms. To this end, the association between self-monitoring using ESM and PGD symptoms was examined. Furthermore, the study focused on the potential relation between perceived personal benefits from participation in ESM research and the severity of PGD symptoms.

Methods: The total sample consisted of 74 bereaved people. First a telephone interview (T1) measuring PGD symptoms was conducted. This was followed by a two-week ESM phase, monitoring PGD symptoms and their contexts. Lastly a second telephone interview was conducted (T2), again measuring PGD symptom and assessing perceived personal benefits after research participation. The relation of PGD scores and self-monitoring was analyzed using a paired T-test, further it was examined whether the frequency of self-monitoring related to the PGD scores. The association between perceived personal benefits and PGD symptoms was examined using linear regression analysis.

Results: Self-monitoring was negatively related to PGD symptoms. The frequency of self-monitoring showed no significant association with the PGD scores. Perceiving more personal benefits was positively associated with PGD symptoms.

Discussion: Self-monitoring might potentially be a useful tool for reducing PGD symptoms, as its frequency showed no significant association to PGD scores, further research is needed to determine what variables cause the decrease of symptoms. Perceived personal benefits are associated with higher PGD scores, suggesting that those with greater needs find participation more beneficial. Future research should replicate and expand upon these findings.

Key words: Prolonged grief, self-monitoring, Experience Sampling Methodology, perceived personal benefits, bereavement.

Introduction

The human experience is invariably intertwined with loss, a part of life that includes both anticipated goodbyes and unforeseen or traumatic partings. The natural human response to the death of a loved one is grief. While grieving is highly individual, many people experience similar symptoms such as shock, anger, guilt, anxiety, loneliness, or depression (Zisook & Shear, 2009). Most bereaved individuals find ways to cope with the loss, and over time, their grief symptoms decrease, allowing them to move forward (Szuhany et al., 2021b). However, for some individuals, the grief remains intense and leads to severe impairment in their daily life. When grief becomes pathological, it is called Prolonged Grief Disorder (PGD).

PGD has recently been incorporated into the Diagnostic and Statistical Manual of Mental Disorders (DSM) and was part of the text revision of DSM-5, referred to as DSM-5-TR, which became available in March 2022 (American Psychiatric Association, 2022; Moran, 2020). The disorder can be diagnosed when the loss has occurred at least a year ago for adults and at least six months ago for children and adolescents. The core symptoms of PGD include intense longing for the person who has passed away or preoccupation with thoughts of the deceased and the circumstances of the loss (American Psychiatric Association, 2022). Additionally, the bereaved individual must experience significant distress or problems performing daily activities. Further, in the last month preceding diagnosis, the bereaved individual must have experienced at least three of the following symptoms daily: identity disruption, marked disbelief about the death, avoidance of reminders of the deceased, intense emotional pain related to the loss, difficulties with reintegration into daily life, emotional numbness, a sense of life being meaningless, intense loneliness, and an exceeding duration of grief based on social, cultural, or religious norms. (American Psychiatric Association, 2022). The decision to introduce PGD into the DSM-5-TR was influenced by extensive research spanning several decades, indicating that a considerable number of individuals were dealing with enduring challenges related to bereavement (American Psychiatric Association, 2022). A systematic review and meta-analysis by Lundorff et al. (2017) on the prevalence of PGD revealed that one in 10 naturally bereaved adults develops PGD. After the text revision of the DSM-5-TR in 2022, prevalence studies revealed that when applying the new set of diagnostic criteria, the prevalence rate was lower than previously suggested. Rosner et al. (2021) found a probable prevalence of 3.3% among bereaved persons, and Treml et al. (2024) found a prevalence rate of 4.7%. Both studies concluded that despite its lower probable prevalence

under the new DSM-5-TR criteria, PGD remains a debilitating disorder that requires attention by researchers and healthcare professionals.

The process of grieving is often associated with the five stages of grief by Dr. Elizabeth Kubler-Ross (1969). Historically, her work marked a positive change in how death and grief is approached. Prior to her research, the subject death was seen as a taboo, both in research and society (Tyrrell et al., 2023). Besides the positive impact on death and grief research, the five stages of grief have been increasingly criticized by contemporary grief researchers (Avis, Stroebe, & Schut, 2021). The main problems with the theory are the lack of empirical evidence and conceptual clarity, as it is unclear what the stages of grief are and what they represent, and explanatory potential, meaning that the stages of grief fail to explain how and why people cope with loss the way they do (Stroebe et al., 2017). Moreover, the belief that grief follows stages could be harmful to those whose experiences do not follow these stages (Avis et al., 2021; Maciejewski et al., 2007). Recent evidence-based research emphasises that grieving is a dynamic process rather than a static state, highlighting the need to investigate how grief changes on a daily basis (Avis et al., 2021; Bonanno & Kaltman, 2001). Prior research examining grief and PGD symptoms has mostly used retrospective measures like surveys or interviews, capturing data at a single time point (Bonanno & Kaltman, 2001; Jordan et al., 2005). This method only captures recalled grief symptoms, not the real-time experience, thereby failing to account for the individual context and fluid nature of grief. Recent experiences are more accurate reflections of grief than those recalled from further in the past.

An alternative method that accounts for this is Experience Sampling Methodology (ESM) (Hektner et al., 2007). ESM involves repeated asking about behaviours and experiences of subjects in real time (Hektner et al., 2007). The participants monitor their behaviours and emotions, while being in their usual environments (Shiffman et al., 2008). ESM is thought to be a more representative methodology to measure and understand grief than retrospective measures. It does not only minimize the likelihood of retrospective bias, but it also enables the documentation of the interplay between cognitive, behavioural, and affective responses over brief time intervals (Myin-Germeys et al. 2018).

Lenferink et al. (2022), recently tested the acceptability and feasibility of measuring PGD symptoms using ESM. Their findings indicated that it is acceptable and feasible to measure PGD symptoms in daily life using ESM, even though compliance and retention are challenging. ESM has the potential to reduce symptoms of PGD through self-monitoring.

Self-monitoring is defined as the systematic observation and recording of target behaviour, such as emotional responses, dysfunctional thoughts, and problem behaviours (Cohen et al., 2013).

In depression research, self-monitoring has been found to lead to greater self-insight like patterns of thought, experience, and behaviour and therefore may result in a positive change of behaviour. In turn, this behaviour change could lead to a reduction in symptoms (Simons et al., 2015; Snippe et al., 2016). In a study examining the use of ESM across different clinical populations setting, including relatives of patients with a psychotic disorder, patients with a psychotic disorder, patients with depression, patients with residual depression and individuals with variable levels of psychometric risk for psychotic disorder, it was found that self-monitoring led to greater feelings of control over their situation and an increased engagement in improving their health (van Os et al., 2017). Furthermore, self-monitoring is cost-effective and easy to use for participants and researchers (Page et al., 2020). However, the relationship between PGD symptoms and self-monitoring has not been sufficiently tested.

Another factor briefly discussed by Lenferink et al. (2022) was that the participation in self-monitoring may be personally beneficial to the participants. Personal benefits could be insight into their own experiences or something the participants value as positive or personally meaningful (Leung, 2013). Parsons et al. (1997) found that perceiving personal benefits of participation are a significant determinant of behaviour change. This has been confirmed by studies investigating the motivators for behaviour change in smoking cessation and prostate cancer screening (McKee et al., 2005; Tingen et al., 1998). In the context of PGD symptomology, this could mean that participants who indicate perceived personal benefits due to participation have a higher motivation to change their behaviour in a positive manner and therefore improve their symptoms in the long run. Therefore, knowing why and whether a study is perceived as personally beneficial is an important factor for participant recruitment and ethical research (Castillo et al., 2011). Nevertheless, many research designs still lack an evaluation of personal benefits after participation (Newman et al., 2004).

Reflecting on what has been discussed about PGD, ESM, self-monitoring, and perceived personal benefits it becomes clear that further research in these fields is needed. Contributing to close this research gab, the present study investigates the associations between self-monitoring, Perceived Personal Benefits and PGD symptoms.

Building on the findings of Lenferink et al. (2022) and the existing research on self-monitoring, it is examined whether self-monitoring is associated with PGD symptoms. Based on prior literature (Simons et al., 2015; Snippe et al., 2016; van Os et al., 2017), it was

hypothesized that self-monitoring is negatively associated with PGD symptoms. Additionally, it was examined whether Perceiving Personal Benefits due to research participation relate to PGD symptoms. Based on the findings of Parsons et al. (1997), McKee et al. (2005) and Tingen et al. (1998), it is hypothesized that greater perceptions of personal benefits are associated with lower PGD symptoms.

Methods

Procedure

This study concerns a secondary analysis of data collected by Lenferink et al. (2022). People were recruited via social media networks and websites directed at bereaved people. By following a link, people accessed an information letter. After providing informed consent, the participants were contacted by master psychology students from the University of Twente. During this initial contact, a telephone interview (T1) was scheduled. Interviews were conducted by the master students, who were trained for this purpose. In T1, several the participants demographics, loss circumstances and PGD symptoms were assessed. On average, T1 lasted 47 minutes. After completing T1, participants received an instruction video via email. In this video it was explained how to install the Ethica app, which was necessary to take part in the ESM phase of the study.

The ESM questions encompassed items related to PGD symptoms as well as contextual factors, including the respondent's current location, companionship, activities, and the type and quality of social interactions. Participants in the ESM phase received five pop-up messages per day for 14 consecutive days. These messages were randomly initiated between 8:30 and 9:30 AM. Subsequently, participants received audible reminders on their phones every three hours at semi-random intervals; from 11:30 AM to 12:30 PM, 2:30 to 3:30 PM, 5:30 to 6:30 PM, and 8:30 to 9:30 PM. If participants did not complete the ESM survey after receiving the message, reminders were again sent 10 and 20 minutes later. Participants had a 60-minute window to complete the ESM survey, which comprised 17 items and typically took about 1 to 2 minutes to complete. In cases where participants missed more than half of the surveys in a day (i.e., three or more surveys), they were contacted via telephone or email to encourage future survey completion. After completing the ESM-phase, participants were contacted again by the master students. This time, the final step of the study participation was scheduled, consisting of a second telephone interview (T2), assessing the participants PGD

levels, items to evaluate the study participation regarding perceived personal benefits, and more.

Prior to data collection, the research design was approved by the ethics board of the faculty of the Behavioural, Management and Social Sciences of the University of Twente, Enschede (number: 211101). The nature and intent of the study were fully disclosed. Participants knew their participation was optional and anonymous, and that dropping out would have no negative consequences. Data collection was carried out from January through March 2022.

Participants

To participate, people must have experienced the loss of a significant other (e.g., partner, friend, or family member) at least three months ago. All participants had to be above the age of 17, fluent in Dutch or German, and have access to a smartphone. To ensure the participation was safe and ethical for all participants, those who indicated at the baseline of the study that they were highly suicidal or diagnosed with a psychotic disorder were excluded. The response options for these questions ranged from "not at all" to "almost every day." Only those who answered "no" to the diagnosis question and "not at all" to the self-harm question were permitted to continue participating in the study. This was done to prevent possible triggers or setbacks. Initially, 80 people were willing to participate. Only those who participated in all study phases (i.e., T1,ESM, and T2) were included in the analyses. The final sample consisted of 74 participants.

Measures

Traumatic Grief Inventory-Clinician Administered (TGI-CA)

At T1 and T2 the PGD symptoms got measured via the Traumatic Grief Inventory-Clinician Administered (TGI-CA). The TGI-CA is the structured interview version of the Traumatic Grief Inventory – Self Report Plus (TGI-SR+) (L. I. M. Lenferink, Eisma, et al., 2022). The TGI-CA consist of 22 items which assess PGD symptoms as defined by the DSM-5-TR and the ICD-11, in addition to other grief disorder criteria (Lenferink et al., 2022).

For this study, the instructions of the TGI-CA were adapted. The original formulation “past month” was replaced with” past two weeks” so it aligns with the ESM phase duration (Lenferink et al., 2022). The participants rated each grief item on a scale from one (never) to five (always). An example is “In the past two weeks, did you feel alone or detached from

others?". The PGD scores were calculated by summing up the item scores. The possible summed scores ranged from 22 to 110. PGD scores ≥71 indicate probable caseness of PGD (Lenferink et al., 2022).

The TGI-CA demonstrated strong validity and reliability in prior research (Lenferink et al., 2022). In the present study the Cronbach's alpha of all TGI-CA items was 0.91 at T1 and 0.94 value at T2.

Frequency of self-monitoring

In the ESM phase the participants were asked to fill out five ESM surveys per day. After the completion of the ESM phase, it was determined how many times each participant completed the ESM surveys. The highest possible frequency rate was 70.

Reactions to Research Participation Questionnaire (RRPQ)

To examine the perceived personal benefits of assessing PGD symptoms in daily life at T2, a subscale of the RRPQ was used. The RRPQ was invented by Newman et al. (2001) and originally consists of 21-items and five subscales. These subscales include Participation Factor, Personal Benefits, Emotional Reactions, Perceived Drawbacks, and Global Evaluation. All items are rated one a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate more positive research evaluation.

For this study, only the Perceived Personal Benefits subscale was required, so only this specific subscale was utilized. The subscale consisted out of four items; the formulations have been adapted to fit the context of the study. For example, "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". The other three items were: "I gained something positive from participating in daily diary measures in the app.", "I found participating beneficial to me.", and "I found participating in this study personally meaningful.". Higher scores indicated greater Perceived Personal Benefits. Psychometric properties of the original and adapted version have shown to be sufficient in various studies (Newman et al., 2001; Waterman et al., 2019). The Cronbach's alpha level for the Personal Benefits subscale in this study was 0.86.

Statistical analysis

The collected data were analysed using R Studio version 4.2.3. The used R-code can be found in Appendix A. In order to examine whether self-monitoring is associated with PGD

symptoms, PGD scores in T1 and T2 were compared. This was done using a paired t-test with a two-sided alpha level of 0.05.

As a proxy measure it was examined whether the frequency of self-monitoring was related to PGD symptoms. This was done by using the number of ESM survey completions and conducting linear regression analysis including PGD scores at T2 and the participants frequency of self-monitoring.

To examine the relationship between perceived personal benefits and PGD symptoms at T2, another linear regression analysis including Perceived Personal Benefit and PGD scores at T2, was conducted.

Results

Characteristics of participants

Seventy-four participants were interviewed in T1, completed the ESM-phase and the T2 interview. Their ages ranged from 22 to 85 years (M = 44.35, SD = 17.09). The majority of the participants was female, German or Dutch, had a university degree, and lost their loved one to a physical illness. See Table 1 for an overview of the demographic characteristics of participants.

Table 1

Demographic Characteristics of Participants (N = 74)

	N	%
Gender		
Female	56	75.68
Male	18	24.32
Country of birth		
Germany	41	55.41
Netherlands	31	41.89
Other	2	2.70
Highest educational level		
Primary school	0	0.00
High school	11	14.86
Vocational education	19	25.67
University	44	59.46

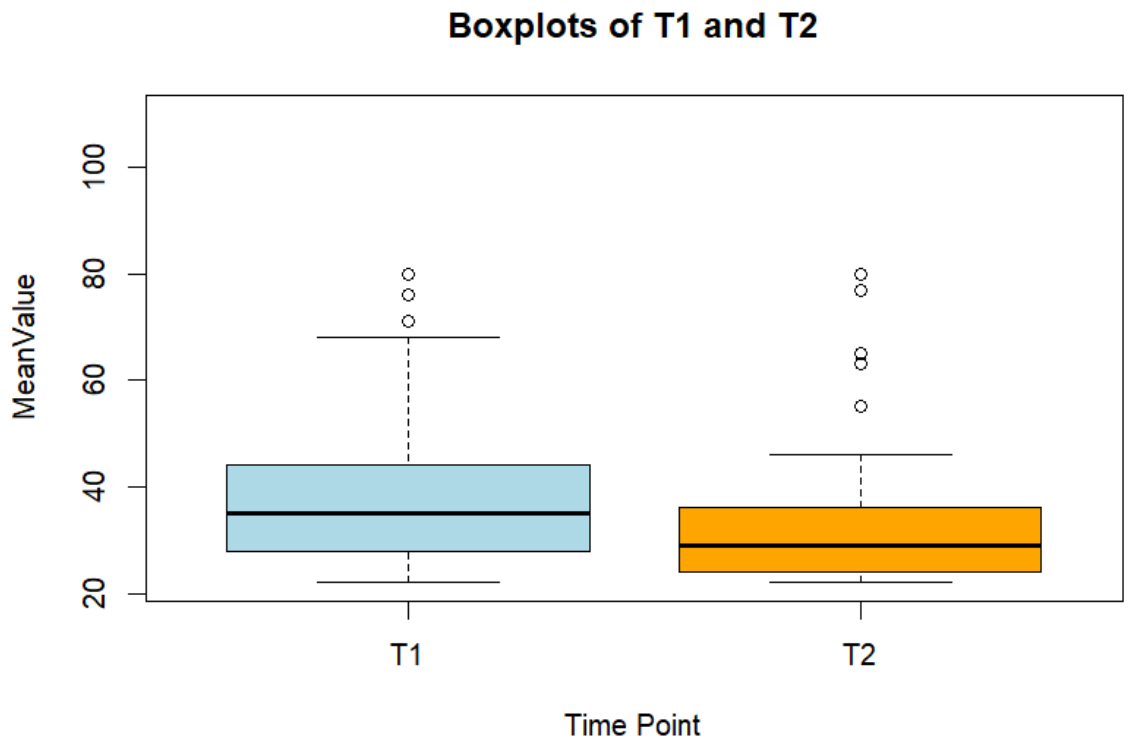
Cause of death		
Physical disease	60	81.08
Accident	1	1.35
Suicide	5	6.75
Homicide/ Murder	1	1.35
Other	7	9.46

Differences of PGD symptoms before and after self-monitoring in the ESM phase

The mean difference between PGD symptoms at T1 (*M* = 37.72, *SD* = 12.72) and T2 (*M* = 32.40, *SD* = 12.09) was found to be statistically significant (*t* = 6.13, df = 73 p < .001, 95% CI [3.58, 7.08]). These results suggest that there is a significant reduction in PGD symptoms when comparing symptoms reported before and after participating in the ESM phase. See Figure 1 for a comparison of PGD symptoms reported before and after the ESM phase.

Figure 1

Variation in PGD symptoms at T1 and T2



Note. PGD = Prolonged Grief Disorder. T1 shows PDG symptoms reported before self-monitoring and T2 after.

The association between frequency of self-monitoring and PGD Symptoms

The association between the frequency of self-monitoring and PGD symptoms at T2 was not significant, ($F(1,72) = 0.99$, $p = .322$). The analysis revealed an R^2 value of .014, indicating that the frequency of self-monitoring only accounts for 1.4% of the variance in PGD symptoms. Thus, the frequency of self-monitoring in the ESM-phase was not related to PGD symptoms.

The association between perceived personal benefits and PGD symptoms

On average, participants perceived the participation as neutral ($M = 2.87$, $SD = 0.97$). The regression model was statistically significant ($F(1,72) = 8.20$, $p = .005$). The results indicate a significant positive relationship between perceived personal benefits and PGD symptoms at T2 (B = 3.96, SE = 1.38). This means that participants with higher levels of perceived personal benefits reported higher levels of PGD symptoms at T2.

Discussion

The first aim of this study was to investigate the association between self-monitoring using ESM and PGD symptoms. As the second aim, it was investigated whether the experience of personal benefits due to participation in ESM research is related to PGD symptoms. The study´s sample consisted out of 74 bereaved individuals.

Main findings

Consistent with findings from other research, predominantly in depression (Kramer et al., 2014), it was hypothesized that self-monitoring is associated with a decrease in PGD symptoms. As anticipated, a significant improvement of PGD symptoms was observed after participating in self-monitoring. It is notable that the frequency of self-monitoring was not related to PGD symptoms. Perceived personal benefits were positively associated with PGD symptoms.

Examining these results in greater detail, the findings of the first hypothesis fit into the broader context of most existing self-monitoring literature (Simons et al., 2015; Snippe et al., 2016). In general, self-monitoring is seen as a promising tool to personalize treatments and decrease symptoms (Folkersma et al., 2021). Further, most researchers, healthcare practitioners and clients view self-monitoring as a great addition to various treatments, as it

increases the self-awareness, illness insight, and self-management. However, not all studies confirm that it is also related to a symptom reduction (Bos et al., 2019). The results of a more recent study by Bastiaansen et al., (2020) do not show an improvement in depression symptoms resulting from self-monitoring. In the present study it did not become clear what underlying factors lead to the improvement of PGD symptoms. Possible reasons could be behaviour change, a greater feeling of control over the situation or an increased dedication to the process of improving their health, as found in the study by van Os et al. (2017). In order to truly understand the reasons why self-monitoring helps to reduce symptomatology, especially in the context of grief studies and PGD symptoms, further research is needed. In addition, a proxy measure was conducted, analysing how the frequency of self-monitoring is related to PGD symptoms, resulting in no significant association between frequency of self-monitoring and PGD symptoms. Currently, this has not been investigated in the context of ESM or grief research. A study by Peterson et al. (2014) on the effects of self-monitoring and long-term success with weight management has also found that the variable frequency of self-monitoring alone, had no significant effect on success in weight management. This changed when including consistency of self-monitoring; frequent and consistent self-monitoring promised long-term success in weight management (Peterson et al., 2014). The consistency of self-monitoring was not included in the analysis of the present study. Nevertheless, if future research confirms consistency of self-monitoring as a significant variable associated with a decrease of PGD symptoms, it would underscore the effectiveness of self-monitoring as an intervention and reduce the likelihood that symptom improvement is merely due to the passage of time. From the current results, the non-significance of frequency of self-monitoring indicates that the improvement of PGD symptoms is due to factors other than self-monitoring, possibly the passage of time.

Overall, the main finding of the study by Peterson et al. (2014) align with the findings of the present study. As previously mentioned, self-monitoring is already an established tool, which is also cost-effective and user-friendly for both participants and researchers (Page et al., 2020). If further research confirms that the frequency of self-monitoring is not related to its decrease in symptomatology, it can be seen as an additional benefit for self-monitoring, as perfect adherence by the participants is not needed.

Regarding perceiving personal benefits due to participation, it was hypothesized that a more positive evaluation is related to lower PGD symptoms. The results were contradicting to the expectations, as a positive evaluation of personal benefits was significantly associated with an increase of PGD symptoms. Generally, there is limited research on the association

between study participation, perceived personal benefits, and symptomatology. Parsons et al. (1997), identified perceived personal benefits as a significant determinant of positive behaviour change. Further, participants of various studies report motivation to change their behaviour in a positive manner as a personal benefit after participating in research (Castillo et al., 2011; Legerski & Bunnell, 2010; MacNeill et al., 2016). In the present study the opposite was the case. A plausible explanation for that could be that those who report more PGD symptoms have a greater need for help and therefore evaluate the study participation as more beneficial to them than participants who report less PGD symptoms. To confirm this supposition additional research is required.

Contributions and Recommendations

The findings of this study further support the potential of self-monitoring using ESM to reduce symptoms of psychopathology and adds to the relatively small body of self-monitoring research, specifically in the context of bereavement. Replication is required to validate these results. Nevertheless, it is presumed that implementing self-monitoring in PGD treatments could result in similar positive outcomes similar to depression treatment. A possible clinical application could be the development of a self-help tool in the form of an application to monitor one´s feelings and symptoms. In the context of depression treatment similar applications have shown good results and acceptance (Hartmann et al., 2019; Kauer et al., 2012; Scherr & Goering, 2019)

Additionally, the study provides a strong incentive to further investigate the perceived personal benefits of participating in research. Although various studies have examined the potential benefits of participating in research, there is a lack of literature on how these perceived benefits relate to symptomatology (Newman et al., 2004; Locock & Smith, 2010). Given that reported benefits, such as increased motivation to change behaviour and greater knowledge about one's situation, have shown positive effects on symptomatology in other research fields, the findings of the present study were unexpected. A qualitative approach to explore what specific benefits participants gain from participating in ESM research is recommended, as it could potentially provide more insights and explanations.

Strengths and Limitations

This study possesses several strengths that are worth emphasizing. In this study two aspects of self-monitoring and ESM research on PGD have been investigated for the first time. First, when examining the association between self-monitoring and PGD symptoms, we also determined whether the frequency self-monitoring plays a role. This is an aspect that has not been taken into account by most studies investigating self-monitoring and to my best

knowledge has not been researched in the context of bereavement (Peterson et al., 2014). Second, this study was the first that investigated whether perceiving personal benefits after research participation in ESM research relates to PGD symptoms. Third, in this study the participants had the chance to gain greater insight into their own behaviour patterns, grief reactions and potentially increase their feeling of control over their grieving process. Before analysing the data, it was not known whether self-monitoring would show a negative association with PGD symptoms. Nevertheless, self-monitoring has proven to increase self-insight in patterns of thought, experience, behaviour as well as one´s feeling of control (Bos et al., 2019; Van Os et al., 2017).

Despite its strengths, the present study also faces several limitations. All participants were gathered through self-selected sampling. This means that a selection bias and a lack of generalizability is possible, as individuals choose to participate based on their own motivations (Babbie, 2020). Second, most participants were female, had a university degree and lost their loved one in a natural way such as an illness. All these aspects limit the generalizability of this research. Following research on understanding the ways men and women mourn by Niemeier (2011), women are often expected to be more emotional. This may lead to a social desirability bias in which women overestimate and men underestimate certain behaviors and emotions (Podsakoff et al., 2003). However, in grief research, gender is generally considered a moderating variable rather than a main variable directly impacting the outcome (Smid, 2020; Stroebe et al., 2001). Further, people with a university degree have been found to generally be overrepresented in research, as they have more favorable views of research and are more willing to participate (Baquet et al., 2006; Reinikainen et al., 2017). Besides that, 81% of the sample lost their loved one due to an illness. This might reduce the generalizability of the findings for people who lost their loved one to unnatural circumstances (e.g. suicide, homicide/murderer, accidents, other).

Third, it cannot be ruled out that part of the improvement in PGD symptoms is due to time passing by and not the self-monitoring. As the effect of time has not been investigated in this study it is advisable to conduct future research with a comparison group. Having a control group that does not participate in the ESM phase would clarify whether the association can be attributed to the passing of time or the self-monitoring of PGD symptoms.

Conclusion

All in all, it can be concluded that self-monitoring has several benefits, whether it might be a useful tool to reduce PGD symptoms needs further research. The frequency of self-monitoring served as a proxy measure and showed no association with PGD symptoms.

Perceived Personal Benefits are associated with higher PGD scores, potentially indicating that participants with higher PGD scores have a greater need for help and therefore evaluate the participation as more beneficial. For future research a more comprehensive analysis of self-monitoring interventions is recommended, including the consistency of self-monitoring and qualitative methods. As ESM is yet not fully established in grief research, not only symptom reduction and personal benefits but also the emotional, social, and financial costs of participation should be assessed.

References

American Psychiatric Association. (2022, May). *Prolonged grief disorder*. https://www.psychiatry.org/. Retrieved February 23, 2024, from https://www.psychiatry.org/patients-families/prolonged-grief-disorder

Ansari, W. E., & Phillips, C. J. (2004). The Costs and benefits to participants in community Partnerships: a paradox? *Health Promotion Practice*, *5*(1), 35–48. https://doi.org/10.1177/1524839903258066

Avis, K. A., Stroebe, M., & Schüt, H. (2021). Stages of Grief Portrayed on the Internet: A systematic analysis and critical appraisal. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.772696

Babbie, E. R. (2020). *The practice of social research*. Cengage AU.

Baquet, C. R., Commiskey, P., Mullins, C. D., & Mishra, S. I. (2006). Recruitment and participation in clinical trials: Socio-demographic, rural/urban, and health care access predictors. *Cancer Detection and Prevention*, *30*(1), 24–33. https://doi.org/10.1016/j.cdp.2005.12.001

Bonanno, G. A., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review*, *21*(5), 705–734. https://doi.org/10.1016/s0272-7358(00)00062-3

Bos, F. M., Snippe, E., Bruggeman, R., Wichers, M., & Van Der Krieke, L. (2019a). Insights of patients and clinicians on the promise of the experience sampling method for psychiatric care. *Psychiatric Services*, *70*(11), 983–991. https://doi.org/10.1176/appi.ps.201900050

Bos, F. M., Snippe, E., Bruggeman, R., Wichers, M., & Van Der Krieke, L. (2019b). Insights of patients and clinicians on the promise of the experience sampling method for psychiatric care. *Psychiatric Services*, *70*(11), 983–991. https://doi.org/10.1176/appi.ps.201900050

Buur, C., Zachariae, R., Komischke-Konnerup, K. B., Marello, M. M., Schierff, L., & O'Connor, M. (2024). Risk factors for prolonged grief symptoms A systematic review and meta-analysis. *Clinical Psychology Review*, *107*, 102375. https://doi.org/10.1016/j.cpr.2023.102375

Castillo, A. G., Jandorf, L., Thélémaque, L. D., King, S., & Duhamel, K. (2011). Reported benefits of participation in a research study. *Journal of Community Health*, *37*(1), 59–64. https://doi.org/10.1007/s10900-011-9416-0

Cohen, J. S., Edmunds, J., 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. https://doi.org/10.1016/j.cbpra.2012.06.002

DePrince, A. P., & Chu, A. (2008). Perceived benefits in Trauma Research: Examining methodological and individual difference factors in responses to research participation. *Journal of Empirical Research on Human Research Ethics*, *3*(1), 35–47. https://doi.org/10.1525/jer.2008.3.1.35

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. https://doi.org/10.1016/j.invent.2021.100436

Hartmann, R., Sander, C., Lorenz, N., Böttger, D., & Hegerl, U. (2019). Utilization of Patient-Generated Data collected through mobile Devices: Insights from a survey on attitudes toward Mobile Self-Monitoring and Self-Management apps for Depression. *JMIR Mental Health*, *6*(4), e11671. https://doi.org/10.2196/11671

Hektner, J. M., Schmidt, J. A., & Csikszentmihalyi, M. (2007). *Experience sampling method: Measuring the Quality of Everyday Life*. SAGE.

Hoe ga je om met rouw - Tips voor complexe rouw - Rouwbehandeling.nl. (2024, March 27). Rouwbehandeling. https://rouwbehandeling.nl/

Jordan, J. R., Baker, J., Matteis, M., Rosenthal, S., & Ware, E. S. (2005). THE GRIEF EVALUATION MEASURE (GEM): AN INITIAL VALIDATION STUDY. *Death Studies*, *29*(4), 301–332. https://doi.org/10.1080/07481180590923706

Kramer, I., Simons, C. J., Hartmann, J. A., Menne-Lothmann, C., Viechtbauer, W., Peeters, F., Schruers, K., Van Bemmel, A. L., Myin-Germeys, I., Delespaul, P., Van Os, J., & Wichers, M. (2014). A therapeutic application of the experience sampling method in the treatment of depression: a randomized controlled trial. *World Psychiatry/World Psychiatry*, *13*(1), 68–77. https://doi.org/10.1002/wps.20090

Legerski, J., & Bunnell, S. L. (2010). The risks, benefits, and ethics of Trauma-Focused research participation. *Ethics & Behavior*, *20*(6), 429–442. https://doi.org/10.1080/10508422.2010.521443

Lenferink, L., Eisma, M. C., Smid, G. E., De Keijser, J., & Boelen, P. A. (2022). 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 (Print)*, *112*, 152281. https://doi.org/10.1016/j.comppsych.2021.152281

Lenferink, L., Franzen, M., Knaevelsurd, C., Boelen, P. A., & Heeke, C. (2022). The Traumatic Grief Inventory-Clinician administered: A Psychometric evaluation of a new interview for ICD-11

and DSM-5-TR Prolonged Grief Disorder. *Social Science Research Network*. https://doi.org/10.2139/ssrn.4212934

Lenferink, L. I., Franzen, M., Klooster, P. M. T., Knaevelsrud, C., Boelen, P. A., & Heeke, C. (2023). 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. https://doi.org/10.1016/j.jad.2023.03.006

Leung, Y. (2013). Perceived benefits. In *Springer eBooks* (pp. 1450–1451). https://doi.org/10.1007/978-1-4419-1005-9_1165

Locock, L., & Smith, L. (2010). Personal benefit, or benefiting others? Deciding whether to take part in clinical trials. *Clinical Trials*, *8*(1), 85–93. https://doi.org/10.1177/1740774510392257

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. https://doi.org/10.1016/j.jad.2017.01.030

Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). An empirical examination of the stage theory of grief. *JAMA*, *297*(7), 716. https://doi.org/10.1001/jama.297.7.716

MacNeill, V., Foley, M., Quirk, A., & McCambridge, J. (2016). Shedding light on research participation effects in behaviour change trials: a qualitative study examining research participant experiences. *BMC Public Health*, *16*(1). https://doi.org/10.1186/s12889-016-2741-6

McKee, S. A., O'Malley, S. S., Salovey, P., Krishnan-Sarin, S., & Mazure, C. M. (2005). Perceived risks and benefits of smoking cessation: Gender-specific predictors of motivation and treatment outcome. *Addictive Behaviors*, *30*(3), 423–435. https://doi.org/10.1016/j.addbeh.2004.05.027

Moran, M. (2020). Board approves new prolonged grief disorder for DSM. *Psychiatric News*, *55*(21). https://doi.org/10.1176/appi.pn.2020.11a12

Myin-Germeys, I., Kasanova, Z., Vaessen, T., Vachon, H., Kirtley, O. J., Viechtbauer, W., & Reininghaus, U. (2018). Experience sampling methodology in mental health research: new insights and technical developments. *World Psychiatry*, *17*(2), 123–132. https://doi.org/10.1002/wps.20513

Newman, E., & Kaloupek, D. G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, *17*(5), 383–394. https://doi.org/10.1023/b:jots.0000048951.02568.3a

Newman, E., Willard, T., Sinclair, R. R., & Kaloupek, D. G. (2001). Empirically supported ethical research practice: The costs and benefits of research from the participants' view. *Accountability in Research*, *8*(4), 309–329. https://doi.org/10.1080/08989620108573983

Niemeier, J. P. (2011). Grieving Beyond Gender: Understanding the Ways Men and Women Mourn, by K. J. Doka & T. L. Martin. *Journal of Women & Aging*, *23*(3), 278–279. https://doi.org/10.1080/08952841.2011.589290

Page, E. J., Massey, A. S., Prado-Romero, P. N., & Albadawi, S. (2020). The Use of Self-Monitoring and Technology to Increase Physical Activity: A Review of the literature. *Perspectives on Behavior Science*, *43*(3), 501–514. https://doi.org/10.1007/s40614-020-00260-0

Parsons, J. T., Siegel, A. W., & Cousins, J. H. (1997). Late adolescent risk-taking: effects of perceived benefits and perceived risks on behavioral intentions and behavioral change. *Journal of Adolescence*, *20*(4), 381–392. https://doi.org/10.1006/jado.1997.0094

Peterson, N. D., Middleton, K. R., Nackers, L. M., Medina, K. E., Milsom, V. A., & Perri, M. G. (2014). Dietary self-monitoring and long-term success with weight management. *Obesity*, *22*(9), 1962–1967. https://doi.org/10.1002/oby.20807

Podsakoff, P. M., MacKenzie, S. B., Lee, J., & Podsakoff, N. P. (2003). Common method biases in behavioral research: A critical review of the literature and recommended remedies. *Journal of Applied Psychology*, *88*(5), 879–903. https://doi.org/10.1037/0021-9010.88.5.879

Prigerson, H. G., Kakarala, S. E., Gang, J., & Maciejewski, P. K. (2021). History and status of Prolonged Grief Disorder as a Psychiatric diagnosis. *Annual Review of Clinical Psychology*, *17*(1), 109–126. https://doi.org/10.1146/annurev-clinpsy-081219-093600

Reinikainen, J., Tolonen, H., Borodulin, K., Härkänen, T., Jousilahti, P., Karvanen, J., Koskinen, S., Kuulasmaa, K., Männistö, S., Rissanen, H., & Vartiainen, E. (2017). Participation rates by educational levels have diverged during 25 years in Finnish health examination surveys. *European Journal of Public Health*, *28*(2), 237–243. https://doi.org/10.1093/eurpub/ckx151

Rosner, R., Comtesse, H., Vogel, A., & Doering, B. K. (2021). Prevalence of prolonged grief disorder. *Journal of Affective Disorders*, *287*, 301–307. https://doi.org/10.1016/j.jad.2021.03.058

Scherr, S., & Goering, M. (2019). Is a Self-Monitoring App for Depression a Good Place for Additional Mental Health Information? Ecological Momentary Assessment of Mental Help Information Seeking among Smartphone Users. *Health Communication*, *35*(8), 1004–1012. https://doi.org/10.1080/10410236.2019.1606135

Shiffman, S., Stone, A. A., & Hufford, M. R. (2008). Ecological Momentary assessment. *Annual Review of Clinical Psychology*, *4*(1), 1–32. https://doi.org/10.1146/annurev.clinpsy.3.022806.091415

Simons, C., Hartmann, J. A., Kramer, I., Menne-Lothmann, C., Hoehn, P., Van Bemmel, A. L., Myin-Germeys, I., Delespaul, P., Van Os, J., & Wichers, M. (2015). Effects of momentary self-monitoring on empowerment in a randomized controlled trial in patients with depression. *European Psychiatry*, *30*(8), 900–906. https://doi.org/10.1016/j.eurpsy.2015.09.004

Smid, G. E. (2020). A framework of meaning attribution following loss. *European Journal of Psychotraumatology*, *11*(1). https://doi.org/10.1080/20008198.2020.1776563

Snippe, E., Simons, C., Hartmann, J. A., Menne-Lothmann, C., Kramer, I., Booij, S. H., Viechtbauer, W., Delespaul, P., Myin-Germeys, I., & Wichers, M. (2016). Change in daily life behaviors and depression: Within-person and between-person associations. *Health Psychology (Print)*, *35*(5), 433–441. https://doi.org/10.1037/hea0000312

Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning Health-Care professionals. *Omega*, *74*(4), 455–473. https://doi.org/10.1177/0030222817691870

Stroebe, M., Stroebe, W., & Schut, H. (2001). Gender Differences in Adjustment to Bereavement: An Empirical and Theoretical review. *Review of General Psychology*, *5*(1), 62–83. https://doi.org/10.1037/1089-2680.5.1.62

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

Tingen, M. S., Weinrich, S. P., Heydt, D. D., Boyd, M. D., & Weinrich, M. C. (1998). Perceived benefits: A predictor of participation in prostate cancer screening. *Cancer Nursing*, *21*(5), 349–357. https://doi.org/10.1097/00002820-199810000-00006

Treml, J., Linde, K., Brähler, E., & Kersting, A. (2024). Prolonged grief disorder in ICD-11 and DSM-5-TR: differences in prevalence and diagnostic criteria. *Frontiers in Psychiatry*, *15*. https://doi.org/10.3389/fpsyt.2024.1266132

Tyrrell, P., Harberger, S., Schoo, C., & Siddiqui, W. (2023, February 26). *Kubler-Ross Stages of Dying and Subsequent Models of Grief*. StatPearls - NCBI Bookshelf. https://www.ncbi.nlm.nih.gov/books/NBK507885/

Van Os, J., Verhagen, S., Marsman, A., Peeters, F., Bak, M., Marcelis, M., Drukker, M., Reininghaus, U., Jacobs, N., Lataster, T., Simons, C., Investigators, E., Lousberg, R., Gülöksüz, S., Leue, C., Groot, P. C., Viechtbauer, W., & 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. https://doi.org/10.1002/da.22647

Waterman, E. A., Edwards, K. M., Dardis, C. M., Kelley, E. L., & Sessarego, S. N. (2019). Assessing intimate partner violence via daily diary surveys: feasibility, reporting, and acceptability. *Journal of Interpersonal Violence*, *36*(19–20), 9121–9142. https://doi.org/10.1177/0886260519865964

Zisook, S., & Shear, K. (2009). Grief and bereavement: what psychiatrists need to know. *World Psychiatry*, *8*(2), 67–74. https://doi.org/10.1002/j.2051-5545.2009.tb00217.x

Appendix A

R-code

```
library(ggplot2)

#creating one dataset
View(df)
df <- ESM1_T1_T2_Wide
df <- df[df$T1_Progress == 100,]
df <- merge(df, Data_number_of_observations, by="QualtricsID")
df <-df[c(33:54, 85:88, 93:114, 1, 7:10, 16, 116)]
df<-na.omit(df)

#checking the demographics
gender_count <- aggregate( T1_Gender ~ QualtricsID, data = df, FUN = function(x) {x[1]})
gender_table <- table(gender_count$T1_Gender)
cat("Number of males:", gender_table["1"], "\n")
cat("Number of females:", gender_table["2"],"\n")

nationality_count <- aggregate( T1_Home_country ~ QualtricsID, data = df, FUN =
function(x) {x[1]})
table(nationality_count$T1_Home_country)

nationality_counts <- table(df$T1_Home_country)
print(nationality_counts)
```

```
education <- table(df$T1_Education)
print(education) #2=high school, 3 =vocational education, 4 = university

cause_of_death <- table(df$T1_cause)
print(cause_of_death) #1=physical disease, 2=accident, 3 =suicide, 4 = homicide/murder, 5 other

unique(ESM1_T1_T2_Wide$T1_Gender)
unique(ESM1_T1_T2_Wide$T1_Home_country)
unique(ESM1_T1_T2_Wide$T1_Education)
unique(ESM1_T1_T2_Wide$T1_cause)

#T-test RQ one
df$T1_mean <- rowSums(df[c(1:22)])
df$T2_mean <- rowSums(df[c(27:48)])

t.test(df$T2_mean, df$T1_mean, paired=TRUE)

# Calculate mean and standard deviation for T1_mean
mean_T1 <- mean(df$T1_mean)
sd_T1 <- sd(df$T1_mean)

# Calculate mean and standard deviation for T2_mean
mean_T2 <- mean(df$T2_mean)
sd_T2 <- sd(df$T2_mean)

# Print the results
cat("Mean of T1_mean:", mean_T1, "\n")
cat("Standard deviation of T1_mean:", sd_T1, "\n")
cat("Mean of T2_mean:", mean_T2, "\n")
cat("Standard deviation of T2_mean:", sd_T2, "\n")

unique(ESM1_T1_T2_Wide$T2_RRPQ_1)
```

```
unique(ESM1_T1_T2_Wide$T2_RRPQ_4)

#RQ two PPB

df$RRPQ_mean <- rowMeans(df[c(23:26)])
mean(df$RRPQ_mean)
sd(df$RRPQ_mean)

cor.test(df$RRPQ_mean, df$T2_mean)

library(dplyr)
df <- mutate(df, PPB = ifelse(RRPQ_mean > 3,"Yes","No"))

out <- lm(T2_mean ~ RRPQ_mean, data=df)
summary(out)

out <- lm(RRPQ_mean ~ T2_mean, data=df)
summary(out)

table(df$PPB)

#checking reliability

install.packages("psych")
library(psych)
psych::alpha(df[c(23:26)]) # reliability for RRPQ
psych::alpha(df[c(27:48)]) # reliability for T2 questionnaire
psych::alpha(df[c(1:22)]) # reliability for T1 questionnaire

#creating boxplot RQ one
data_matrix <- cbind(df$T1_mean, df$T2_mean)

## Create the boxplot using the matrix
boxplot(data_matrix, col = c("lightblue", "orange"), names = c("T1", "T2"),
```

```
      main = "Boxplots of T1 and T2", xlab = "Time Point", ylab="MeanValue")

#controling for frequency of self-monitoring
out <- lm(df$T2_mean ~ df$NcompleteAPP2)
summary(out)

install.packages("lubridate")
library(lubridate)

#additional analysis for method section
# Convert date of birth to Date object
df$T1_DoB <- dmy(df$T1_DoB)

# Create a new variable for the age of participants
df$age <- as.integer((Sys.Date() - df$T1_DoB) / 365.25)

#Calculate descriptives
mean(df$age)
sd(df$age)
```