CONSEQUENCES AND AFTERCARE OF A TRAUMATIC LOSS OF A LOVED ONE

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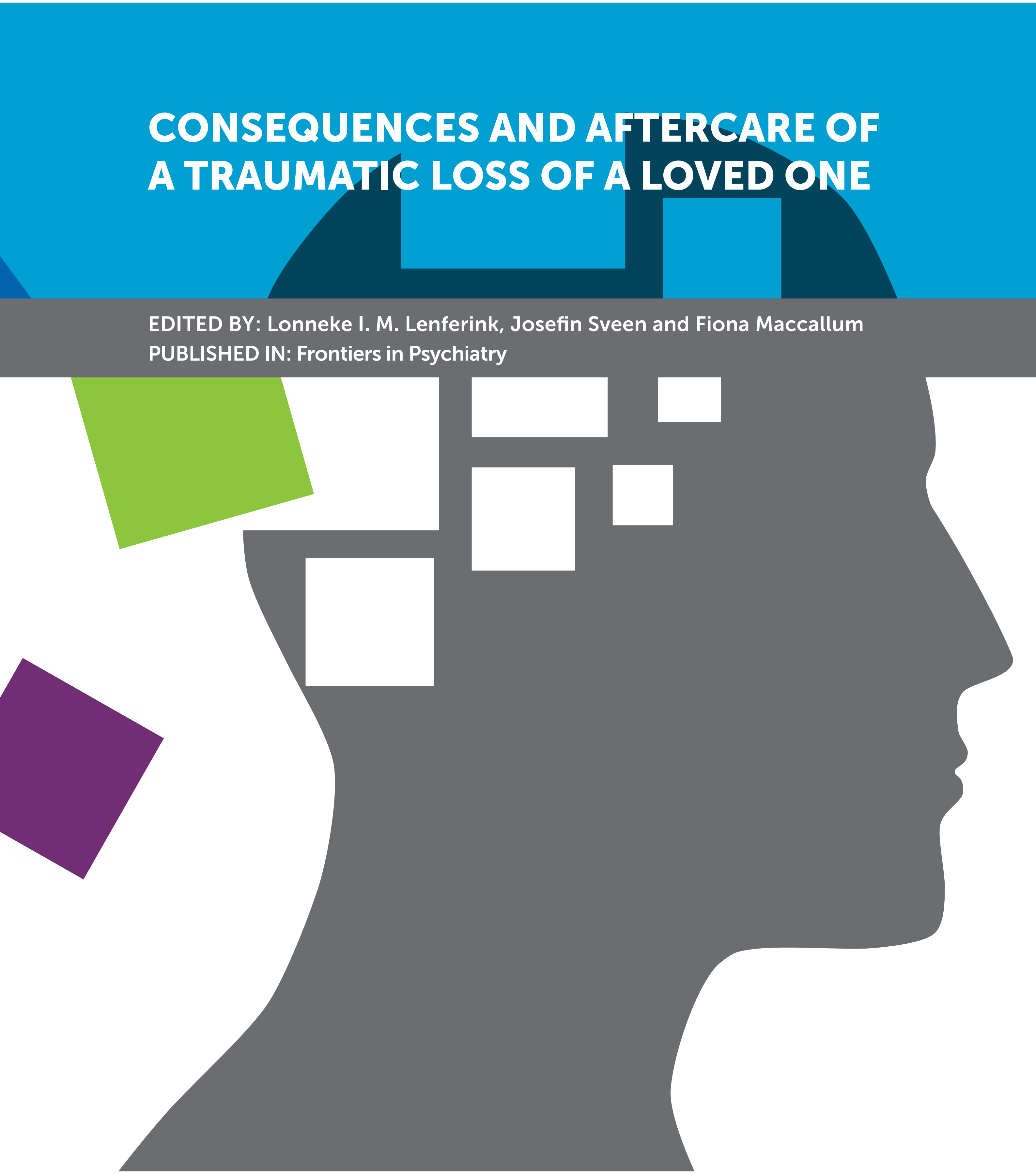

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CONSEQUENCES AND AFTERCARE OF A TRAUMATIC LOSS OF A LOVED ONE

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Editorial: Consequences and aftercare of a traumatic loss of a loved one

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grief, bereavement, loss, death, trauma

Editorial on the Research Topic
Consequences and aftercare of a traumatic loss of a loved one

The potential long-term negative health impacts associated with bereavement have been recognized with the entry of Prolonged Grief Disorder (PGD) into the most recent editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) (1) and International Classification of Diseases (ICD-11) (2). People who are confronted with the traumatic loss of a loved one, such as a sudden, violent, or unnatural loss, are at greater risk of developing mental disorders, including PGD, posttraumatic stress disorder (PTSD), and depression than non-traumatically bereaved people (3–6). In this special issue, we are pleased to present nine articles on the consequences and aftercare of a (traumatic) loss of a loved one. Comprising quantitative, qualitative, and theoretical approaches, the papers were (co-)written by 42 authors from institutes based in Europe, North America, and Oceania; Eight of nine leading authors were women. Included in the empirical studies are 7,763 bereaved adolescents/adults who have experienced varied losses including a death during the COVID-19 pandemic (Dominguez-Rodriguez et al.), death of a child (Eklund et al.), and the long-term disappearance of a family member (Wayland and Ward). The papers also challenge the field to think about the extent to which currently accepted findings apply across individuals with different cultural backgrounds including Arab and Sub-Saharan Africans with a refugee background (Lechner-Meichsner and Comtesse) and black Americans (Wilson and O'Connor).

Four studies focus on severity of distress post-loss. In a Mexican sample ($N = 5{,}224$) prevalence rates and correlates of survey-based distress were examined in people who accessed an online support platform for bereavement during the pandemic. Two thirds of participants reported problematic grief reactions and 90% reported clinically relevant anxiety, depression, and/or sleep problems. A recent suicide attempt was the strongest correlate of post-loss distress (Dominguez-Rodriguez et al.). This study suggests that bereavement during the pandemic may increase the risk for post-loss distress.

In a study including a convenience sample of 433 Dutch and German bereaved adults interviewed by telephone, Heeke et al. examined patterns of comorbidity among PGD, PTSD, and depression symptoms using latent class analysis. This analysis identified three classes that differed in symptom intensity, rather than being qualitatively different. Characteristics often observed in traumatic loss, including unexpectedness of the loss and less meaning making were associated with classes with more pervasive distress levels.

Doering et al. further investigated the role of unexpectedness in a representative German sample ($N = 811$). Loss of a child was most strongly related to PGD outcomes, however, perceived unexpectedness of the death was associated with both PGD caseness and PGD severity. Together, these studies highlight features of traumatic loss that can place individuals at risk for poor outcomes.

Additionally, Mitima-Verloop et al. investigated a different set of risk factors for poor bereavement outcomes, namely the inability to undertake culturally accepted grief rituals in a diverse bereaved sample (representing 32 nationalities mostly from European countries). In their timely cross-country survey-study they compared disturbed grief levels and evaluations of funeral rituals between people who experienced a loss before ($N = 50$) or during the pandemic ($N = 182$). While a more negative general funeral evaluation was related to higher grief levels, grief levels and funeral evaluations did not differ between the two groups (Mitima-Verloop et al.). Their findings highlight the overall importance of funeral practices and cultural rituals around death.

Two papers investigate processes that may be targeted to reduce grief related distress. Eklund et al. pilot-tested a self-help mobile-app (based on cognitive-behavioral theories) providing parents who had lost a child with psychoeducation, support, and exercises such as exposure to avoided aspects of the loss ($N = 13$), using a mixed-method design. The app seemed feasible and acceptable to participants and preliminary findings showed decreases in symptoms across the trial. While this paper highlights the need for interventions targeting (prolonged) grief, especially early in the grief process, and how technology can be applied to improving grief outcomes, more research in larger samples is needed.

Another important cognitive process underlying PGD is poor loss-related memory integration. Smith et al. described the development and evaluation of a scale to measure loss-related memory characteristics in three independent bereaved community samples (total $N = 1{,}001$). The scale showed excellent psychometric properties, and a cross-lagged panel analysis showed that memory characteristics predicted later PGD symptoms. The scale offers a new tool for targeting memories during PGD treatment and should facilitate novel research on memory processes in grief.

Two studies consider whether current conceptualization of grief can be applied cross-culturally. Lechner-Meichsner and Comtesse used a mixed-methods approach to explore beliefs about PGD among Arab and Sub-Saharan African refugees living in Germany. Similarities with western conceptualizations regarding causes and "cures" were found, such as suddenness of the death and needs for emotional processing. However, potential cultural and context-specific features relevant to help-seeking behaviors were also identified. Findings highlight the importance of a culture-sensitive treatment-approach for PGD in refugees. Wilson and O'Connor question the application of current conceptualizations of grief, which focus only on the individual, across cultures. In this thought-provoking piece, they outline a novel theoretical model for understanding collective grief amongst Black Americans, a group regularly underrepresented in the literature. The model describes how the historical and ongoing racial violence, economic dispossession and structural inequality experienced by black Americans has shaped a grief that is both quantitatively and qualitatively different from current conceptualizations as of grief as an individual response to loss. In recognizing the collective nature of grief, the model also proposes an important role for grief as a catalyst for social action for black Americans.

Wayland and Ward expand the discussion of grief further to explore the experiences of Australian families living with the ambiguous loss of a missing person. This mixed-methods paper focused on the experience of providing a DNA sample for the purpose of body identification. The authors draw attention to a range of contextual and procedural factors that can exacerbate or lessen the distress associated with this process, suggesting important procedural changes to improve the system for relatives of missing people.

Grief is a complex phenomenon. The inclusion of a formal PGD diagnosis in classification systems provides an important opportunity to consider how we, as a field, would like to progress. Taken together, we anticipate this diverse set of papers will enhance knowledge on assessment, prediction, and treatment of distress in traumatically bereaved people, as well as highlight similarities and differences across cultures and contexts. We are pleased to see the increased application of sophisticated statistical techniques and mobile technology to study grief *in situ* and provide support to individuals in their daily lives. We hope that international collaborations, such as this special issue, and the ongoing application of rigorous and varied methodological approaches will continue to offer significant potential to improve outcomes for those struggling following the loss of a loved one.

Author contributions

LL, JS, and FM co-edited this research topic. LL wrote the first draft of the manuscript. JS and FM wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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ORIGINAL RESEARCH
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Prevalence of Anxiety Symptoms and Associated Clinical and Sociodemographic Factors in Mexican Adults Seeking Psychological Support for Grief During the COVID-19 Pandemic: A Cross-Sectional Study

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The COVID-19 pandemic is one of the greatest challenges in modern history, with more than four million confirmed deaths worldwide. To date, evidence regarding the psychological impact of the COVID-19 pandemic on grievers is scarce for developing countries such as Mexico. This study aimed to assess the levels of anxiety and associated concerns in a sample of Mexican adults bereaved during the COVID-19 outbreak. A cross-sectional study was conducted through the *Duelo COVID* (COVID Grief) platform, which is a self-guided online treatment. A total of 5,224 participants reported their anxiety, depression, sleep quality, avoidance, and arousal, prolonged grief symptoms, and medication consumption. Independent sample Mann-Whitney *U*-tests, chi-square tests, and Kruskal-Wallis tests, as well as multinomial logistic regression, were conducted. Results indicated that 90.4% of the participants reported clinical levels of anxiety, depression, and sleep affectations. The people who lost someone during the last 5 months scored higher in normal grief symptoms compared to the people whose loss was 6 months ago or more, and 9.8% of individuals reported the use of prescription medication, with anxiolytics and antidepressants being the most common. Females, younger respondents, unemployed people with a lower educational level, and participants who disclosed a recent suicide attempt were among those who reported medication consumption. Sleep problems were more frequent in older participants.

Keywords: COVID-19, grief, anxiety, depression, sleep quality, post-traumatic stress, drugs, Mexico

INTRODUCTION

The 2019 coronavirus disease (COVID-19) has wreaked major havoc on people's mental health worldwide (1). Recent findings showed a significant increase in clinical disorders like anxiety, depression, post-traumatic stress disorder (PTSD), and insomnia (2). Shah et al. (3) reported that 50.9% of their adult sample suffered from anxiety, 57.4% from stress, and 58.6% from depression. Wang et al. (4) systematically reviewed 68 studies comprising 288,830 participants from 19 countries and found that 33% of adults reported symptoms of anxiety or depression. Likewise, Xiong et al. (5) conducted a systematic review in which they observed that the prevalence of anxiety symptoms ranged from 6.33 to 50.9%, and was often comorbid with depression at rates from 14.6 to 48.3%. Before the pandemic, Medina-Mora et al. (6) reported that in 2018, among 5,826 Mexican adults, the rate of anxiety disorder was 14.3%, followed by mood disorders at 9.2%.

During the pandemic, Pérez-Cano et al. (7) found that in a sample of 613 Mexican adults, 48% reported mild to severe anxiety, and 18% reported depression or moderate-to-severe stress. González-Ramírez et al. (8) examined the psychological impacts of COVID-19 prevention measures in a sample of 3,932 participants from the Mexican population, and observed that 943 participants showed intrusive thoughts, 933 avoidance, and 515 hyperarousal symptoms. The researchers also found that 1,160 participants showed symptoms of clinically significant post-traumatic stress. Avoidance responses included denial of the event's significance and consequences, blunted sensation, and awareness of emotional numbness (9). On the other hand, arousal included anger, irritability, hypervigilance, and difficulty concentrating (10).

Within these studies, predictors of anxiety, depression, stress, and PTSD included being under the age of 40, being of female gender, being divorced or widowed, having a lower education level, suffering from poorer health, feeling alone, living in urban areas (5), and having poor sleep quality (11). Wang et al. (4) identified that higher odds of anxiety and depression were related to COVID-19 infection risk that included suspected or confirmed cases, suffering from pre-existing physical or mental conditions, and longer media exposure. Likewise, it has been found that the population who contracted COVID-19 along with those with pre-existing diseases, particularly chronic/degenerative pathologies, or other psychiatric disorders were related to higher levels of anxiety and depression (12). Anxiety has also been associated with poor sleep quality in the context of the COVID-19 pandemic (13), as well as potentially increased rates of abuse of psychotropic medication and illegal drugs (14), as means to cope with suffering.

A section of the population that may be particularly impacted during the pandemic are those who have experienced a bereavement (15). According to the World Health Organization (WHO), as of July 12, 2021, there were 5,570,163 deaths due to COVID-19 since the beginning of the pandemic (1).

Mexico is the fourth highest place in terms of deaths due to COVID-19. This means there are now millions of families that are currently grieving a person who has died from COVID-19, not to mention other causes on death (16).

Experiencing a sudden loss, such as those brought on by COVID-19, may have a significant impact on those left to grieve (13). Kokou-Kpolou et al. (16) indicated that death circumstances during the pandemic due to the viral contagion of COVID-19 deprive families of assisting the dying person and partaking in associated rituals or ceremonies, provoking an increase in emotional pain and raising the likelihood of pathological grief outcomes. Other factors that might complicate the grieving process include feelings of guilt, the restrictions imposed on funerals to share emotional pain with others, and the isolation prior to the loss (17, 18), as well as anticipatory grief that could lead to mental health complications in both the surviving family and the medical staff (18).

Given these risk factors and psychological needs, the online intervention *Duelo COVID*, a self-guided treatment that provides psychological intervention aimed at preventing the development of complicated grief in the Mexican population during the COVID-19 pandemic, was created (19). This online platform was designed for those who have experienced a bereavement during the pandemic, regardless if it was due to COVID-19 or another cause during the pandemic. It consists of 12 sessions with the aim to assist participants in resolving conflicts associated with a higher risk of grief complications and to improve wellbeing in different areas of the affected people's lives. This study was carried out as a result of the data obtained from *Duelo COVID* to further our understanding of the impact of bereavement during COVID-19 on levels of psychological distress in Mexico. Specifically, the study explored levels of anxiety, depression, sleep quality, avoidance, arousal, prolonged grief symptoms (also known as complicated grief), and medication consumption with the aim of better understanding the needs of this vulnerable population.

METHODS

Study Design and Participants

The first step in the analysis was the selection of participants who met the inclusion criteria. Using non-probability sampling and a cross-sectional design, 12,798 participants were recruited from those who had accessed *Duelo* COVID from mid-December 2020 to mid-March 2021. After excluding 3,683 individuals who had not signed the informed consent form, the included participants were those who had completed the pre-evaluation questionnaires, were aged 18 years or older, and had accessed the platform from Mexico ($N = 5{,}224$). **Figure 1** shows the sample filtering flow chart. Sociodemographic characteristics of the final sample are presented in **Table 1**.

Psychological Measures

Generalized Anxiety Disorder 7-Item

The GAD-7 is a 7-item scale designed to measure the severity of symptoms of generalized anxiety disorder (20). Items range from 0 (*not at all*) to 3 (*nearly every day*), with a possible score ranging from 0 to 21. A cut-off point of 5 or above is an indicator

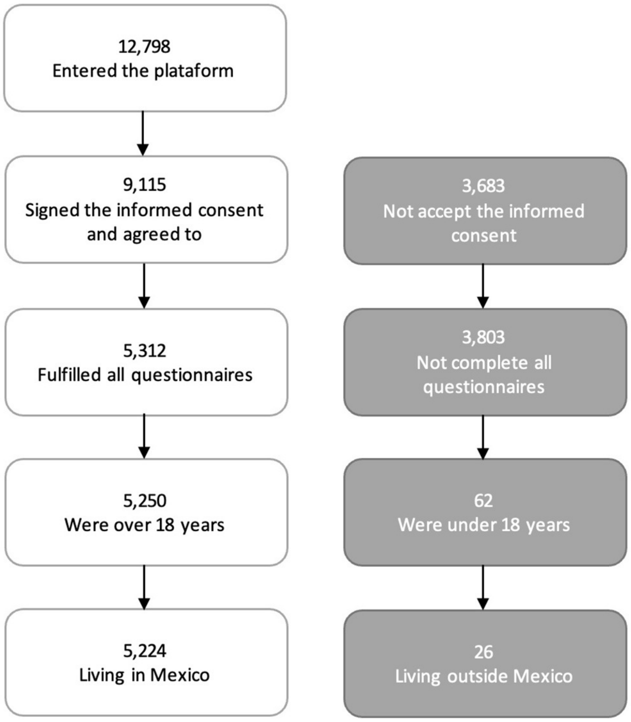

FIGURE 1 | Sample filtering flow chart.

of probable anxiety symptoms. Additional cut-off criteria were used to explore the severity of those symptoms: GAD7 ≥10 and GAD7 ≥15 for moderate and severe presentations, respectively (20, 21). In the current study, Cronbach's alpha = 0.90.

Center for Epidemiologic Studies Depression Scale

The CESD-R is a self-report scale that enquires about symptoms of depression during the past 2 weeks. It consists of 20 questions with answers ranging from *rarely* or *never* (<1 day) to *most of the time* (5–7 days). Scores of 16 or above indicate probable depression diagnosis (22). This measure has been commonly used in health research, and its psychometric properties have shown it to be a valid scale in the Mexican population (Cronbach's alpha >0.90) (23). In this study, Cronbach's alpha was 0.93.

Pittsburgh Sleep Quality Index

The PSQI assesses sleep quality patterns. Seven areas are evaluated including subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, daytime dysfunction, and use of sleeping medication. A total score ranging from 0 to 21 is provided by the sum of the seven mentioned factors. A score of five or above indicates poor sleep quality (24). In the present study, we will report this total score. The measure has demonstrated reliability in the Mexican population ($\alpha = 0.78$) (25). In the current study, Cronbach's alpha = 0.70.

Post-traumatic Stress Disorder Symptom Scale Self-Report

The PSS-SR is a 17-item semi-structured self-report measure that can be administered to examine post-traumatic symptoms. Each item is answered using a four-point scale ranging from 0 (*not at all*) to 3 (*very much*). The instrument presents adequate reliability values ($\alpha = 0.85$) (26, 27). In the present study, two of the three dimensions of this scale were considered (due to their link with anxiety): avoidance ($\alpha = 0.82$) and increased arousal/ activation ($\alpha = 0.76$) of physical, cognitive, or behavioral symptoms derived from post-traumatic stress. Both will be considered for the data analysis.

Inventory of Complicated Grief

The ICG (28) is a self-report measure composed of 19 items that assess emotional, cognitive, or behavioral symptoms of complicated grief (CG). For this study, the Spanish version of Limonero et al. (29) was applied. Items range from 0 (*never*) to 4 (*always*), with a total score ranging from 0 to 76. A cut-off point over 30 in the total ICG score was used to explore potentially maladaptive grief symptoms. The validation of the scale in the Mexican population was performed by the authors of the present study and the preprint version is available at Dominguez-Rodriguez et al. (30) In the current study Cronbach's alpha = 0.93.

Sociodemographic Information

Participants were asked to report their gender and, in a binary *yes/no* format, their employment status, if they were currently receiving psychological treatment, and if in the last 3 months they had attempted to take their own life. They were also asked to inform about any medications they were taking at the time of the study.

Three other socio-demographic variables were re-coded as follows: age (≤30 years old; ≥31 years old), educational level (≤12 years; ≥13 years), and time since loss (<6 months; ≥6 months). These cut-off scores were decided upon for the following reasons: the age of 30 is commonly used for separating young adults from adults. Twelve years represent the average time spent in mandatory education in the countries where the participants of this study reside. The time frame of 6 months or more, elapsed since the loss, is used to assess the presence of persistent and potentially problematic symptoms of grief, as proposed by the ICD-11 (31). Initially, these last three variables were, respectively, continuous (for age) and eight-point ordinal variables (for educational level and time since loss).

Procedures

From December 22, 2020, to March 16, 2021, participants accessed the online platform and completed the informed consent form followed by the questionnaires. At the end of the survey, the participants were notified about available online psychological counseling services, if the users were identified as being at risk after answering the questionnaires (e.g., recent attempts of suicide, moderate to high results on the suicide scale, diagnosis of posttraumatic stress disorder), and if the participants did not have access to the intervention, they were

TABLE 1 | Sociodemographic characteristics of support-seeking bereaved adults during the COVID-19 pandemic.

	Anxiety				Depression				Sleep				Avoidance				Arousal			
(*n*; %)	**Mdn [IQR]**	***U***	***p***	***r***	**Mdn [IQR]**	***U***	***p***	***r***	**Mdn [IQR]**	***U***	***p***	***r***	**Mdn [IQR]**	***U***	***p***	***r***	**Mdn [IQR]**	***U***	***p***	***r***
Gender																				
Female (4,559; 87.3)	14.00 [9.0]	1263,413.50	<0.001	0.13	34.00 [22.00]	1302,141.50	<0.001	0.11	12.00 [5.00]	1303,528.00	<0.001	0.11	11.00 [8.00]	1366,469.00	0.001	0.08	8.00 [6.00]	1239,724.00	<0.001	0.14
Male (654; 12.5)	12.00 [9.0]				29.00 [23.00]				11.00 [5.00]				10.00 [8.00]				7.00 [6.00]			
Age in years																				
≤30 (2,406; 46.1)	14.00 [8.00]	3057,441.00	<0.001	0.09	34.00 [21.00]	3109,338.00	<0.001	0.07	12.00 [5.00]	3127,007.00	<0.001	−0.09	12.00 [7.00]	2897,484.50	<0.001	0.13	9.00 [5.00]	3066,456.50	<0.001	0.08
≥31 (2,818; 53.9)	13.00 [10.00]				32.00 [23.00]				12.00 [5.00]				10.00 [8.00]				8.00 [6.00]			
Working																				
Yes (3,100; 59.3)	13.00 [9.00]	3111,541.00	0.001	−0.05	31.00 [22.00]	2882,809.50	<0.001	−0.11	12.00 [5.00]	3182,040.50	0.039	−0.03	10.00 [8.75]	3058,002.50	<0.001	−0.06	8.00 [6.00]	3073,392.00	<0.001	−0.06
No (2,124; 40.7)	14.00 [8.00]				35.00 [21.00]				12.00 [5.00]				11.00 [8.00]				9.00 [5.00]			
Education in years																				
≤12 (1,243; 23.8)	14.00 [8.00]	2316,243.00	0.001	0.06	37.00 [20.00]	2011,024.00	<0.001	0.16	12.00 [5.00]	2284,995.00	<0.001	0.07	11.00 [8.00]	2272,448.50	<0.001	0.07	9.00 [6.00]	2247,605.50	<0.001	0.08
≥13 (3,981; 76.2)	13.00 [9.00]				32.00 [22.00]				12.00 [5.00]				10.00 [8.00]				8.00 [6.00]			
Psychological support																				
Yes (402; 7.7)	14.00 [9.00]	934,214.00	0.897	–	31.00 [23.00]	868,311.50	0.013	−0.07	12.00 [6.00]	929,888.50	0.776	–	10.00 [8.00]	851,912.50	0.002	−0.08	8.00 [6.00]	892,732.00	0.108	–
No (4,666; 89.3)	13.50 [9.00]				33.00 [22.00]				12.00 [6.00]				11.00 [8.00]				8.00 [6.00]			
Medications																				
Yes (513; 9.8)	17.00 [7.00]	847,752.50	<0.001	0.24	39.00 [19.00]	895,476.50	<0.001	0.20	15.00 [5.00]	677,575.50	<0.001	0.36	13.00 [8.00]	981,975.00	<0.001	0.13	10.00 [6.00]	904,497.00	<0.001	0.19
No (4,555; 87.2)	13.00 [8.00]				32.00 [22.00]				12.00 [5.00]				11.00 [8.00]				8.00 [6.00]			
Suicide attempt																				
Yes (164; 3.14)	18.00 [6.00]	242,889.00	<0.001	0.35	48.00 [13.00]	169,010.00	<0.001	0.50	14.00 [5.00]	276,594.50	<0.001	0.27	15.00 [6.00]	216,171.50	<0.001	0.41	12.00 [5.00]	228,894.00	<0.001	0.38
No (4,904; 93.9)	13.00 [9.00]				32.50 [22.00]				12.00 [5.00]				11.00 [8.00]				8.00 [6.00]			
Time since loss																				
<6 months (4,264; 84.6	14.00 [9.00]	1702,076.00	0.751	–	33.00 [22.00]	1567,541.50	<0.001	0.08	12.00 [5.00]	1615,503.00	0.009	0.05	11.00 [8.00]	1703,215.50	0.774	–	8.00 [6.00]	161,913.50	0.012	−0.05
≥6 months (804; 15.4)	13.00 [9.00]				31.00 [22.00]				12.00 [5.00]				11.00 [8.75]				9.00 [6.00]			

Mdn, Median; IQR, interquartile range; r, Rosenthal's r. Missing data: n, 11 (0.2%) for gender, and n, 156 (3.0%; the same participants) for psychological support, Medication intake, Suicide attempt, and Time since loss.

informed about other available free psychological services. Also, one excluded participant requested their data to be removed from the data analysis.

The study design and procedures were approved by the Research Ethics Committee of the Autonomous University of Ciudad Juárez, México (Approval ID: CEI-2020-2-226) and is registered in Clinical trials (NCT04638842).

Statistical Analysis

Data analyses were performed using SPSS statistical software version 23.0. The prevalence of anxiety, depression, sleep problems, and grief symptoms was expressed as raw scores and percentages of cases and was calculated using the following cut-off scores: for anxiety, GAD-7 $\geq$5; for depression, CESD-R $\geq$16; for sleep problems, PSQI >5, and for potentially problematic grief, ICG >30. The prevalence rates of the two post-traumatic stress factors (avoidance and activation) were not calculated, because we used only two factors (and not the full scale), and we do not have a cut-off point that allows this threshold to be established. The normality and homoscedasticity were calculated for all the dependent variables by the Kolmogorov-Smirnov and the Levene tests, respectively. Independent sample Mann-Whitney *U*-tests were used to explore the sociodemographic characteristics of the participants, including gender, age, working status, educational level, medication intake, psychological treatment, suicide attempt in the last 3 months, and time since loss of the loved one, as well as the total scores of anxiety, depression, sleep problems, avoidance and activation (arousal), and grief symptoms. Rosenthal's *r* was computed to assess the magnitude of the effect for the statistically significant differences obtained from the comparative analyses (32).

Pearson's correlations were used to explore the bivariate correlations among the continuous variables of this study (depression, sleep problems, avoidance, and increased arousal), as a first step to test multicollinearity.

A Chi-square test was performed to compare two independent groups when categorical variables were used, whereas the Kruskal Wallis test was used for comparing more than two groups in a quantitative variable. Chi-Square and Kruskal-Wallis tests, with Cramer's V and Epsilon Squared, respectively, were also performed to compare sociodemographic characteristics and clinical correlates among different groups of participants regarding anxiety severity: individuals who did not present significant anxiety symptoms (GAD-7 = 1–4), and those with mild (GAD-7 = 5–9), moderate (GAD-7 = 10–14), and severe (GAD-7 = 15–21) levels. Multinomial logistic regression was used to quantify the effects of sociodemographic variables on symptoms of anxiety. Significant associated variables identified from the chi-square tests were entered into logistic regression. The Nagelkerke-R^2 was used to examine the percentage of variance associated with anxiety that was explained by the categorical predictors. Adjusted odds ratio with 95% confidence intervals were also reported to measure the strength of association. To identify the relationship between anxiety level and medication use, chi-square and Cramer's V were calculated.

RESULTS

Clinical Symptoms and Sociodemographic Characteristics

There were 4,895 (93.7%) respondents who reported symptoms of anxiety that were rated as mild or above (GAD $\geq$5); 4,972 (95.2%) had clinically relevant sleep problems (PSQI >5), 4,526 (86.6%) presented mild or greater depression symptoms (CESDR $\geq$16). Of those, 4,724 (90.4%) were high across the three areas. Potentially problematic grief symptoms were displayed by 3,538 (67.7%) (ICG >30).

As presented in **Tables 1**, **2**, female gender, under 30 years old, unemployed, lower educational level, taking medication, and made a recent suicide attempt were associated with higher levels of anxiety, depression, posttraumatic stress symptoms (avoidance and activation), and grief symptoms. The results were similar for sleep difficulties; however, older rather than younger age was associated with having difficulties.

Regarding the impact of time since the loss of the loved one, participants whose loss was more recent (<6 months) showed higher levels of depression ($p < 0.001$), sleep difficulties ($p < 0.01$), and problematic grief symptoms ($p < 0.001$), compared to respondents whose loss occurred 6 months ago or more. On the contrary, individuals whose loss occurred more recently (<6 months prior) reported lower levels of arousal than participants with a loss that occurred 6 months ago or more. No significant differences were found for anxiety and avoidance when comparing the participants considering time since the loss (**Supplementary Tables 1–5**).

Correlates of Anxiety Severity

Table 3 summarizes the comparisons between anxiety levels (none, mild, moderate, and severe anxiety) and their correlates. Chi-square analyses were significant for all binary variables, except for psychological support and for time since loss. That is, gender, age, working status, educational level, use of medication, and recent suicide attempt were associated with anxiety.

Kruskal-Wallis tests showed that the more severe the anxiety, the higher the levels of depression, sleep difficulties, avoidance, arousal, and grief symptoms. H values were statistically significant (all $p < 0.001$).

Regarding age, a different trend was observed: the more severe the anxiety, the lower the mean age of the participants. The H value was statistically significant ($p < 0.001$).

Categorical variables with significant *p*- values were included in the multinomial logistic regression.

Next, a multinomial logistic regression was undertaken to examine the extent to which individual variables remained significant predictors of anxiety accounting for shared variance among predictors. Age was considered a binary variable for a more comprehensive interpretation. The reference category was the non-anxiety group. Each level (*mild, moderate, severe*) was compared with this reference category. The multinomial logistic

TABLE 2 | Levels of complicated grief symptoms by sociodemographics.

Variable		Mdn (IQR)	*U*	*p*	*r*
Gender	Female	40 (24)	1183,546.00	<0.001	−0.09
	Male	35 (26)			
Age	≤30 years old	41 (24)	2912,204.00	<0.001	−0.09
	≥31years old	38 (25.75)			
Work status	Employed	38 (24)	2845,588.50	<0.001	−0.08
	Unemployed	42 (23)			
Psychological treatment	Yes	36 (26)	813,396.50	<0.001	−0.06
	No	40 (24)			
Medications	Yes	43 (25)	1045,481.50	<0.001	−0.06
	No	39 (24)			
Suicide attempt	Yes	54 (19)	224,144.00	<0.001	−0.14
	No	39 (24)			
Educational level	≤12 years	44 (22)	1979,192.00	<0.001	−0.12
	≥13 years	38 (25)			
Time since loss	<6 months	40 (24)	1529,027.50	<0.001	−0.07
	≥6 months	36 (27)			

Mdn, Median; IQR, interquartile range; r, Rosenthal's r.

regressions and adjusted odd ratios were calculated and are shown in **Table 4**.

The final model had a−2 Log Likelihood value of 499.560, χ^2 (18, N = 5,056) =249.952, $p < 0.001$. The Nagelkerke Pseudo R-Square was 0.053, which suggested that ∼5.3% of the variance associated with anxiety levels was explained by the predictors.

Moderate and severe anxiety groups exhibited significant associations with gender, age, and substance intake. The influence of these variables was strong. Regarding gender, women were 1.6–2.2 times more likely than men to exhibit problematic anxiety symptoms, adjusting for the rest of the variables. Younger participants were 1.7–1.9 times more likely to be in these anxiety groups (vs. the reference group) than older ones, when controlling for the other predictors. Comparatively, participants who used medication had a risk of 3.3–5.6 times greater of being in the moderate anxiety and severe anxiety groups (vs. the reference group) compared to those who did not use substances, even when controlling for other independent variables. In addition, the severe anxiety group also showed an association with recent suicide attempts: participants had almost 15 times more risk of exhibiting these manifestations of anxiety than people without a recent suicide attempt. On the other hand, working status and level of education were not significant predictors of anxiety severity.

As mentioned in previous paragraphs, we reported the associations between anxiety and medication use, the latter presented in a dichotomous variable format (yes/no). Next, the type of medication and the connection with anxiety levels are explored and shown in **Table 5** (**Supplementary Table 6** presented international non-proprietary names for the substances, also the number and percentage of users for each of them).

From the total sample ($N = 5{,}224$), 513 (9.80%) individuals informed the use of medication. A total of 354 (6.8%) of the respondents reported consuming more than one substance. Antidepressants were the most frequently reported medication. In this category, selective serotonin reuptake inhibitors (SSRIs) were the most frequently used, with 233 (4.5%) participants using one of them and 6 (0.1%) subjects taking two of these substances. Anxiolytics were the second group of medicines most frequently mentioned; within this type, benzodiazepines (BZDs) were the most common with 209 (4.0%) participants reporting the use of one kind of this medication, and 3 (0.1%) respondents who acknowledged taking two different kinds of them.

Chi-square tests presented a significant association between anxiety and BZD ($p < 0.001$). Cramer's V was 0.191 ($p < 0.001$), which suggested that the two variables shared about 3.6% of their variance. The adjusted residual for participants with more severe anxiety presentation was 4.0 (>1.96 in absolute value), indicating that for respondents of this group who were taking BZD, and observed frequencies ($n = 150$) were higher than expected ($n = 128$). None of the other types of drugs showed significant relationships with anxiety.

DISCUSSION

The main objective of this study was to examine the prevalence of anxiety symptoms and associated clinical and sociodemographic factors in Mexican adults seeking psychological support for grief during the COVID-19 pandemic. The results showed that 93.7% of participants exhibited significant anxiety symptoms, 95.2% had sleep problems, 86.6% presented symptoms of depression, and 67.7% showed potentially problematic grief symptoms.

The literature currently available regarding the mental health impact caused by COVID-19 is accumulating, and information from low-income and developing countries is starting to appear, but at a considerably lower rate than in developed countries. A

TABLE 3 | Associations between anxiety levels and predictor variables.

	Anxiety symptoms										
	No (n = 329)		**Mild (n = 1,097)**		**Moderate (n = 1,533)**		**Severe (n = 2,265)**				
Predictors	***N***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	**X^2**	***p***	**Cramer's V**
Gender									37.07	<0.001	0.084**
Female	266	5.8	926	20.3	1,329	29.2	2,038	44.7			
Male	63	9.6	169	25.8	200	30.6	222	33.9			
Total	329	6.3	1,095	21.0	1,529	29.3	2,260	43.4			
Age †									46.48	<0.001	0.094**
≤30 years old	114	4.7	440	18.3	724	30.1	1,128	46.9			
≥31 years old	215	7.6	657	23.3	809	28.7	1,137	40.3			
Total	329	6.3	1,097	21.0	1,533	29.3	2,265	43.4			
Working									17.91	<0.001	0.059**
Yes	212	6.8	701	22.6	886	28.6	1,301	42.0			
No	117	5.5	396	18.6	647	30.5	964	45.4			
Total	329	6.3	1,097	21.0	1,533	29.3	2,265	43.4			
Education									11.07	0.011	0.046*
≤12 years	66	5.3	232	18.7	364	29.3	581	46.7			
≥13 years	263	6.6	865	21.7	1,169	29.4	1,684	42.3			
Total	329	6.3	1,097	21.0	1,533	29.3	2,265	43.4			
Psychological support									2.20	0.534	–
Yes	27	6.7	88	21.9	105	26.1	182	45.3			
No	295	6.3	968	20.7	1,382	29.6	2,021	43.3			
Total	322	6.4	1,056	20.8	1,487	29.3	2,203	43.5			
Medication									82.21	<0.001	0.127**
Yes	10	1.9	59	11.5	133	25.9	311	60.6			
No	312	6.8	997	21.9	1,354	29.7	1,892	41.5			
Total	322	6.4	1,056	20.8	1,487	29.3	2,203	43.5			
Recent suicide attempt									56.37	<0.001	0.105**
Yes	1	0.6	10	6.1	38	23.2	115	70.1			
No	321	6.5	1,046	21.3	1,449	29.5	2,088	42.6			
Total	322	6.4	1,056	20.8	1,487	29.3	2,203	43.5			
Time since loss									0.04	0.998	–
≥6 months	51	6.3	166	20.6	238	29.6	349	43.4			
<6 months	271	6.4	890	20.9	1,249	29.3	1,854	43.5			
Total	322	6.4	1,056	20.8	1,487	29.3	2,203	43.5			
	Mdn	IQR	Mdn	IQR	Mdn	IQR	Mdn	IQR	*H*	*p*	E^2_R
Age †	35.00	16.00	34.00	16.00	31.00	15.00	31.00	13.00	44.047	<0.001	0.008
Depression	13.00	12.50	21.00	16.00	31.00	17.50	42.00	16.00	1,431.690	<0.001	0.274
Sleep problems	8.00	5.00	10.00	5.00	12.00	4.00	14.00	5.00	661.118	<0.001	0.127
Avoidance	4.00	6.00	7.00	6.00	10.00	6.00	14.00	7.00	1,123.558	<0.001	0.215
Activation	3.00	3.00	5.00	4.00	8.00	4.00	11.00	4.00	1,791.972	<0.001	0.343
Grief symptoms	18.00	18.00	28.00	21.00	39.00	19.00	49.00	20.00	1,295.775	<0.001	0.254

† *The age variable is shown as a quantitative and categorical. *$p < 0.05$; **$p < 0.001$.*

part of the population that is potentially suffering more severely than the general population due to the ongoing pandemic is represented by the people that have been bereaved during the COVID-19 pandemic, where funerals and other important rituals were not allowed to take place. Regarding this group, Eisma et al. (33) warned that prolonged grief disorder will be a public health problem once the COVID-19 pandemic ends. Circumstances of death during the pandemic are likely to increase the prevalence of a prolonged grief disorder, such as multiple and indirect traumatic characteristics, such as possible multiple deaths for families that could lead to bereavement overload, due to limitations caused by COVID-19 that restrict families from spending the last days together with the person they lost and from performing on-site funerals (16). Other authors suggest that further research is necessary on the impact of COVID-19 on grievers.

TABLE 4 | Multinomial logistic regression for anxiety.

	Adjusted odds ratio					
	Mild		Moderate		Severe	
Predictors	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Gender						
Female	1.34 (0.97–1.85)	0.079	1.60 (1.16–2.19)	0.004	2.18 (1.59–2.99)	<0.001
Age						
≤30 years old	1.31 (1.00–1.70)	0.049	1.70 (1.32–2.19)	<0.001	1.90 (1.48–2.44)	<0.001
Working						
No	0.93 (0.71–1.21)	0.571	1.15 (0.89–1.49)	0.292	1.11 (0.86–1.44)	0.411
Education						
≤12 years	1.11 (0.81–1.53)	0.514	1.23 (0.90–1.68)	0.189	1.35 (1.00–1.83)	0.052
Drugs						
Yes	1.92 (0.97–3.80)	0.063	3.32 (1.72–6.40)	<0.001	5.64 (2.96–10.73)	<0.001
Recent suicide attempt						
Yes	2.90 (0.37–22.76)	0.312	7.20 (0.98–52.77)	0.052	14.93 (2.07–107.67)	0.007

The results showed that being younger was associated with greater symptomatology in anxiety, depression, grief, avoidance, and arousal. Individuals younger than 30 had more severe symptoms than those older than 30. In previous research, it has been observed that young adults may engage in negative thinking as a coping strategy, which would bring about maladaptive outcomes (34). Importantly, older adults tend to have more stable jobs with better salaries (35), which could act as a protective factor.

In addition, the present study shows a high prevalence of posttraumatic stress related symptoms. These symptoms were higher for females than for males. Also, unemployed people presented more avoidance and arousal symptoms than employed ones, highlighting this group as one of the most affected by the pandemic. This supports prior research showing that unemployment is directly linked to insecurity about work and finances and worse mental health in terms of anxiety and depression (35). It has also been observed that during the COVID-19 pandemic, women were 24% more likely to permanently lose their jobs than men. In addition, women expected their labor income to fall 50% more than men (36). Also, considering the available literature and the results of the present study, there is evidence that during the COVID-19 pandemic, women are more affected than men in terms of mental health. The reasons could be several, such as domestic violence, parenting, miscarriage, pregnancy, job loss, or postpartum depression (37, 38).

Furthermore, attempt of suicide in the last 3 months had significantly greater symptomatology or impact in all the areas measured in this study (anxiety, depression, sleep quality, grief, avoidance, arousal, and medications consumed), compared to the participants that had not recently attempted suicide. These results are in accordance with previous studies. A study conducted with middle-aged and older adults with depressive symptoms in five low- and middle-income countries, concluded that the participants with poor or very poor sleep quality had a greater likelihood of suicidal ideation, and those with moderate and severe or extreme insomnia had a greater likelihood of suicidal ideation and suicidal attempt (39). Other studies identified that anxiety is a statistically yet weak predictor of suicide ideation and attempts but not deaths (40). Another study has observed that suicide attempters and completers were similar in terms of depression, but suicide completers were more likely to use alcohol or medication (41). The results of our study add to the growing literature on mental health outcomes following bereavement during the pandemic. Future studies will assist in establishing the generalizability of our findings. On the other hand, time since loss was also relevant, indicating that people with a more recent loss were more affected in grief areas than those who reported more time since their loss. Additionally, the participants whose loss was <6 months prior to the assessment showed higher levels of depression and of sleep difficulties compared to those whose loss occurred 6 months or more prior to their access to the platform. However, individuals whose loss occurred <6 months ago reported lower levels of arousal compared to participants with a loss that occurred 6 months or more before their first access to the platform. This result reflects the need for future longitudinal studies to understand the trajectory of normal grieving and its relationships with post-traumatic stress symptoms over time. Whereas, studies with participants diagnosed with prolonged grief disorder have shown associations between this disorder and post-traumatic symptoms, including hyperarousal (42), the link between normal grieving and arousal trajectory, considering time since loss, is still scarce. More evidence is required considering the causes of death (natural vs. unnatural causes), the presence of a traumatic vs. a non-traumatic loss (43), and the closeness with the deceased person.

No significant differences were found for anxiety and avoidance when comparing the participants on time since loss. These results may suggest that, concerning the time elapsed since the loss, even after 6 months, people continue to display

TABLE 5 | Medication use and types and their relationship to anxiety.

Medication Type	Users	Anxiety symptoms					
		No	Mild	Moderate	Severe		
	n	*n*	*n*	*n*	*n*	X^2	*P*
Antidepressants							
SSRI						0.54	0.910
Yes	239	4	29	60	146		
No	274	6	30	74	164		
Other						2.21	0.530
Yes	61	0	6	19	36		
No	452	10	53	115	274		
Anxiolytics							
BZD						18.67	<0.001
Yes	212	3	13	46	150		
No	301	7	46	88	160		
Other						1.33	0.723
Yes	24	0	4	7	13		
No	489	10	55	127	297		
Antipsychotics						2.36	0.491
Yes	56	0	5	13	38		
No	457	10	54	121	272		
Anticonvulsant						1.54	0.700
Yes	39	0	6	9	24		
No	474	10	53	125	286		
Natural, naturist, homeopathic						3.20	0.362
Yes	46	1	4	17	24		
No	467	9	55	117	286		
Other substances						6.26	0.095
Yes	11	1	0	5	5		
No	502	9	59	129	305		
Unspecified						8.13	0.067
Yes	19	2	1	5	11		
No	494	8	58	129	299		

indicators of emotional distress, specifically posttraumatic stress symptoms (avoidance and arousal) that, in turn, are associated with high levels of anxiety. This is consistent with the presence of depressive and post-traumatic symptoms that have been reported as frequent among people who have experienced a recent loss (44).

Furthermore, researchers worldwide are concerned about the impact of the circumstances of the COVID-19 pandemic and the possible rise in the prevalence of prolonged grief disorder (45). In this sense, a recent study (46) compared the grief symptomatology in participants that had lost someone due to COVID-19 with those who lost someone due to natural causes, such as other illnesses or old age, and unnatural causes, such as accidents, suicide, or homicide. The researchers observed that, as a result of COVID-19, grievers reported more severe symptoms of prolonged grief disorder and persistent complex bereavement disorder compared to natural bereavement, but not to unnatural bereavement. Likewise, the study of Eisma and Tamminga (47) compared the results of individuals who lost someone before and during the pandemic, observing that in general, grief severity was not significantly different; nevertheless, the people that experienced a recent loss (according to the authors 5 months ago and less) during the pandemic had higher grief levels compared to a similar experience not during the pandemic. These results could suggest that a more recent loss in terms of time is related to higher symptomatology during the COVID-19 pandemic. Another study with recently bereaved spouses observed considerable somatic symptoms during the earliest months of the loss but there were no major health declines over the first year and a half due to the grief symptoms (48). Similarly, Tang and Xiang (49) reported that in a sample of 422 participants who had lost someone due to COVID-19, the prevalence of prolonged grief disorder was between 29.3 and 37.8%, depending on the screening tool.

It is relevant to notice that the vast majority of the participants in this study indicated reduced sleep quality. The sleep quality was significantly lower for older adult participants. Also, analyzing the relationship between the time since loss and sleep quality, significant differences were found (difficulties were greater for those whose loss was more recent). This is in line with the data of other developing countries like Mexico, such as India, where it has been observed that the lockdown was associated with poor sleep quality and shifts in sleep cycles (50). Data from other countries, such as Portugal, indicated that from 365 participants, two-thirds reported at least one sleep difficulty and frequent awakenings (51). To the best of our knowledge, this is the first study that presents data related to sleep quality of bereaved individuals during the COVID-19 pandemic. The research related to sleep disturbances of people suffering from complicated grief is still scarce. It has been observed that in community-dwelling middle-aged and older adults, persons with normal and complicated grief had both a shorter sleep duration and a lower sleep quality, mainly explained by depressive symptoms (52). In the study of Szuhany et al. (53) with 395 patients with complicated grief, greater complicated grief was associated with poorer sleep quality. More research is needed in this line and it is expected that this manuscript provides more data in this line.

Regarding medication consumption, the main medications used were SSRIs, followed by BZDs. A total of 513 individuals reported having consumed medication, and of those, more than half acknowledged taking more than one. This is a considerable proportion, and further studies should be conducted to gain a better understanding of using medication as a coping strategy related to the COVID-19 pandemic. Furthermore, it has been widely observed that alcohol consumption has increased during the COVID-19 pandemic (54), although the WHO discourages the use of substances with the potential to create addiction to manage the burden of social isolation (55), BZDs are often the first-line pharmacological treatment for various anxiety disorders such as General Anxiety Disorder and Social Anxiety Disorder, among others (56). Although there is no confirmed diagnosis of the participants of this study, it was found that severe anxiety symptoms are present in a large part of the sample, symptoms that, due to the significant association found with BZD, are probably being addressed through these medications. These findings give way to a reflection on possible difficulties derived from its use, especially in the medium or long term. This is an aspect that should be included in future studies.

Despite the limitation of the cross-sectional design used in this study, the results presented are relevant because they reveal the high rate of symptoms in bereaved people during the pandemic, specifically the levels of anxiety, depression, affected sleep quality, avoidance and arousal, complicated grief symptoms, and medication consumption. The present results are in line with other studies that have used a cross-sectional design during the COVID-19 pandemic (57, 58). It is recommended that future studies focus on evaluating the trajectory of the grief symptoms of people that lost someone during the COVID-19 pandemic.

Another limitation to the current study was the lack of a comparison group to evaluate the difference in clinical indicators between those who were bereaved and those who were not bereaved during the pandemic. Therefore, the results should be received with caution.

A further limitation is that this study had a considerably a greater sample of women, compared to men. This is in accordance with many other studies where women are less reluctant to search for psychological support than men (59). Also, it has been observed that the prominent obstacles for men to search for psychological help are disinclination to express emotions or concerns about health, embarrassment, anxiety, fear, and poor communication with health professionals, which applies not only to psychological support but also to physical health (60). Another reason could be that men's ideas regarding masculinity are a considerable barrier to seek psychological support (59). It is of interest to researchers that these stereotypes persist even in such a stressful time for humankind, such as this global pandemic. Future studies should make more efforts to include more men in the samples by creating advertisements indicating that it is positive and acceptable for men to ask for psychological support.

Moreover, it must be mentioned that there was no data collected on the cause of death. This information could have been useful in teasing out the differences in anxiety (and associated factors) based on loss due to COVID-19 vs. other causes. Other relevant variables could be added, such as socioeconomic status (61) or social connections (62) of the responder, among other variables, which could influence the psychological impact of the loss. In addition, the sample included only those who sought psychological help. Regarding the strengths of the study, several can be mentioned. This is one of the first studies that has presented the symptomatology of anxiety, depression, sleep quality, avoidance, arousal, grief, and medication consumption in a sample of people that are in a grieving process and actively seeking psychological support due to the loss of someone during the COVID-19 pandemic. Part of this strength is that the sample size was considerably large, with 5,224 participants. Other studies in similar developing countries could be considered in order to further explore the impact of the pandemic on grief.

CONCLUSION

In conclusion, with these results, it has been observed that the most affected sector of the Mexican population with symptoms of anxiety, depression, avoidance, arousal, and grief are unemployed young women that consume medication and have attempted suicide in the last 3 months.

A more recent loss (<6 months prior to participating in the study) was significantly associated with higher levels of depression, sleep difficulties, and grief symptoms, and with lower levels of post-traumatic arousal symptoms, when compared to a loss that occurred 6 months ago or more.

These results indicate the need to provide mental health treatment to the population that suffered the death of a loved one during the COVID-19 pandemic to reduce the impact in terms of mental health, even when the pandemic is under control. In addition, the results of the efficacy of the intervention *Duelo COVID* will be presented in upcoming manuscripts.

DATA AVAILABILITY STATEMENT

Original datasets are available in a publicly accessible repository: The original contributions presented in the study are publicly available. This data can be found here: https://www.datafirst.uct.ac.za/dataportal/index.php/catalog/865.

ETHICS STATEMENT

The study design and procedures were approved by the Research Ethics Committee of the Autonomous University of Ciudad Juárez, México (Approval ID: CEI-2020-2-226) and are registered in Clinical trials (NCT04638842). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

AD-R, PH-A, JM, EE, and LF accessed and verified the underlying data and take responsibility for the integrity of the data and accuracy of the corresponding analysis. AD-R, AR-G, MH, EB, RC, CA-S, PA-L, and SM-L conceptualized the study. PH-A and LF maintained data over time and linked data across data collection waves over time. PH-A, JM, EE, and LF did the formal analyses. AD-R and FR-M acquired the funding for this study. AD-R was the project administrator and supervisor. RM, EB, and JM conducted the literature review and organization of the manuscript. All authors wrote the original manuscript draft, contributed to reviewing, editing the manuscript, had full access to all the data, and had ultimate responsibility for the decision to submit the manuscript for publication.

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SUPPLEMENTARY MATERIAL

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Psychometric Characteristics of the Oxford Grief Memory Characteristics Scale and Its Relationship With Symptoms of ICD-11 and DSM-5-TR Prolonged Grief Disorder

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Difficulties with loss-related memories are hypothesised to be an important feature of severe and enduring grief reactions according to clinical and theoretical models. However, to date, there are no self-report instruments that capture the different aspects of memory relevant to grieving and adaptation after bereavement over time. The Oxford Grief–Memory characteristics scale (OG-M) was developed using interviews with bereaved individuals and was subject to exploratory and confirmatory factor analyses in a community sample ($N = 676$). Results indicated the scale was unidimensional and demonstrated excellent psychometric properties. The impact of memory characteristics on symptoms of Prolonged Grief Disorder (PGD) according to both ICD-11 and DSM-5-TR criteria were investigated using cross-lagged structural equation modelling in a three-wave longitudinal sample ($N = 275$) at baseline and 6 and 12 months later. Results indicated that loss-related memory characteristics predicted future symptoms of PGD after controlling for autoregressions, and concurrent associations between symptoms and memory characteristics. Cross-lagged associations between memory characteristics and symptoms were significant in the first 6 months of follow-up. After that, memory characteristics predicted future symptoms, but not the other way round. Theoretical and clinical utility of the scale and its features are discussed.

Keywords: prolonged grief disorder (PGD), bereavement, memory, structural equation modelling (SEM), cross-lagged analyses, cognitive behavioural therapy

INTRODUCTION

Following a bereavement, severe and enduring grief is thought to persist in approximately 7–14% of grievers (1, 2). In recent years several sets of diagnostic criteria have been developed to measure severe and enduring grief (3–5). While the respective criteria and thresholds for diagnosis differ, all describe persistent yearning or longing for the deceased person and disturbances in thoughts, feelings and behaviours that result in an impairment of functioning.

Theoretical models of prolonged grief hypothesise that symptoms of grief result from a failure to integrate information about the reality of the loss into the autobiographical memory base (6–8). Shear and colleagues proposed that grief symptoms arise as a result of a mismatch between the reality of the death and the mental representation of an attachment figure as being both emotionally and proximally available (8). Boelen and van den Hout (6) similarly suggest that there is a failure to integrate the reality of the loss into the person's existing mental representation of one's self and the world. Maccallum and Bryant (7) emphasise the role of mourning to revise the self-memory system, a system proposed to reciprocally link to the autobiographical memory database (9). They propose that symptoms arise as a result of the discrepancy between an individual's internal self-identity and real-life experiences that challenge the coherence of that identity. Grief adaptation and resolution of symptoms are thought to result from loss-related memory integration within the autobiographical memory base (6, 7) or attachment-related long-term memory (8). Given the important role of memory integration in prolonged grief, an investigation of the characteristics of loss-related memories is of clinical and theoretical interest.

Posttraumatic Stress Disorder (PTSD), like prolonged grief, can also be conceptualised as a disorder that arises from a failure of memory integration of an extremely upsetting event (10, 11). For example, investigations into the characteristics of unwanted intrusive memories in PTSD revealed that these are distressing with vivid perceptual content, disconnected from their context, and are experienced in the "here and now" (12, 13) and thus lead to a sense of current threat for the individual (10). Understanding these characteristics has directly informed advances in therapeutic interventions. For example, stimulus (trigger) discrimination (14) is a therapeutic procedure technique aimed at enhancing the discrimination between triggers in everyday life and trauma memories by training individuals to identify and focus their attention on differences between the trigger in the present moment and its context and the corresponding stimulus during the trauma (10, 15).

Previous investigations of the characteristics of memory associated with severe and enduring grief have focused on the content of intrusive imagery (16) and overgeneral memory (17, 18). Our focus on loss memory characteristics draws on the concept of re-experiencing from the PTSD literature and on in-depth qualitative research investigating memory characteristics in PGD. For example, characteristics of involuntary memories are understood to extend beyond pictures in the mind's eye to include bodily reactions, sudden emotions that are out of context, "affect without recollection," see (10), and also behavioural impulses such as running away or an urge to try to find the deceased person. Recent research with bereaved individuals with and without a probable diagnosis of prolonged grief investigated the triggers, valence, content, intrusiveness, unrealness, and physical and emotional consequences of loss-related memories (i.e., memories associated with the deceased or their death) (19). Four themes emerged related to intrusive imagery: memories that indicated a change for the worse, illness-related imagery, positive memories of the lost person and images of the deceased in the present. Further themes in this work described qualities of memory such as negative memories taking precedent over other memories of the deceased, happy memories causing pain, and memories being characteristically distressing, vivid, with a sense of reliving the memory or the presence of the deceased. Participants who experienced prolonged grief were more likely to describe triggers for their loss memories. These were associated with specific times (e.g., time of day or year), seeing other couples or families and internal emotional or physical states.

The content of the interviews informed a series of items aimed to measure multiple features of memory associated with symptoms of PGD. These include descriptions of loss-related memories as intrusive and distressing in people with PGD (19), as well as memories of the deceased being closely connected to the death event (e.g., "*When I try to remember good times we have shared, memories of the loss pop up*") giving rise to predominantly negative emotions (e.g., *"Even nice memories cause me to feel significant pain*"). Distressing memories were reported as easily triggered (e.g., "*Many different things trigger distressing memories of the loss*") and activated in response to specific cues such as seeing others with their partners or families. Prior memories of the past and experiences with the deceased highlighted the incongruence of self-image since the loss (e.g., "*When I remember things we did together it feels like I am no longer the same person*") and memories without the deceased both positive and neutral were less accessible (e.g., "*I struggle to remember positive times without [-]*"). Memories of the loss were also connected to the emotions felt at the time of the loss (e.g., *"When I remember the loss, I feel the same emotions I felt at the time*") and had a sense of "nowness" (e.g., *'To what extent were you reliving your experience from the loss?'*). Memories also involved a sense of visceral changes in the bereaved individual's body in the form of pain (e.g., "*The physical pain of loss is something I carry everywhere*"), or physical deficit (e.g., "*The loss feels as if part of my body is missing*").

To date, there is no self-report scale that captures the memory characteristics that may be associated with symptoms of prolonged grief. Such a tool could aid clinicians in their decision-making by highlighting the characteristics of memory associated with prolonged grief that need to be targeted in treatment. The scale could also perform as a process measure allowing investigation of potential mediation effects to better understand clinical outcomes. Finally, the scale could inform adaptations to treatment for individual patients. For example, if a patient endorsed high triggering of intrusive memories by many cues in everyday life, this would indicate clinical intervention focused on stimulus discrimination prior to loss memory work. Previous research has highlighted the importance of exposure to distressing memories in treating prolonged grief (20) but to our knowledge, there are no questionnaires that would give clinicians direction on which aspects of memory associated with severe and enduring grief to focus on or that could be used to monitor the process of changes in loss memories with treatment.

To address this gap, we present a new loss-specific measure, The Oxford Grief Memory Characteristics Scale

(OG-M). Developed from interviews described in Smith, Rankin and Ehlers (19), this instrument assesses the characteristics of loss-related memories following bereavement. The aim of this paper is to provide psychometric reliability and validity, including factorial and predictive validity for the OG-M and the OG-M-S, a shortened clinician version for use in clinical settings. Furthermore, we aimed to establish whether the memory characteristics measured with the OG-M predict higher grief severity over time when accounting for prior symptom levels.

MATERIALS AND METHODS

Participants and Procedure

Three separate samples of bereaved individuals were recruited via social media advertisements, bereavement charity mailing lists, and the Google content network in the United Kingdom. Demographics and loss characteristics for each sample are described in **Table 1**. Factorial and psychometric validity and scale reduction were confirmed using 676 adults. Test-retest reliability was assessed with another sample of 50 individuals who completed the OG-M twice with a 1-week gap.

A third three-wave longitudinal sample assessed in the first 6 months after bereavement and again 6 and 12 months later consisted of 275 adults and was used to assess the effect of the scale over time.

Questionnaire data were collected online and followed an ethical framework for internet research (21). All participants were compensated for their time and informed consent was obtained electronically in accordance with ethical approval given by the University of Oxford Medical Sciences Inter-Divisional Research Ethics Committee (MS-IDREC-C1-2015-230; MS-IDREC-C1-2015-231).

TABLE 1 | Sample demographics and loss characteristics.

Variable	**Sample**		
	Cross-sectional (*N* = 676)	**Test-retest (*N* = 50)**	**Longitudinal (*N* = 275)**
Age M (SD)	49.22 (12.52)	51.46 (14.54)	46.43 (13.24)
Women (%)	81.5	84.0	78.5
Months since loss M (SD)	56.91 (79.79)	23.74 (48.44)	2.94 (2.01)
Violent loss (%)	19.5	26.0	9.1
Who died? (%)			
Partner	36.1	28.0	30.2
Child	21.0	22.0	8.7
Sibling	6.5	0.0	5.8
Parent	28.3	42.0	38.2
Another close relative or non-relative	8.2	8.0	17.1

Violent loss defined as resulting from human (in)action (i.e., suicide, homicide, accident, unintentional overdose, and medical negligence) vs. illness.

Measures

Cognitive Measures

The Oxford Grief–Loss-Related Memory Characteristics Scale (OG-M)

Questionnaire items were developed from interviews with bereaved individuals to assess difficulties with memory following their loss (19). Face and content validity were determined in collaboration with bereaved service users and therapists experienced in the treatment of traumatic bereavement leaving 27 questionnaire items from a potential pool of 40 items. The questionnaire asks participants to rate on a 5-point scale (0–not at all to 4–very strongly) the extent to which each statement regarding their memory of the loss applied to them during the last month. Twenty-three items probed memory triggers and their consequences (e.g., "*I am reminded of the loss for no apparent reason*"), qualities of memory (e.g., "*Memories of things we did together are painful*"), the poor availability of positive memories (e.g., "*I struggle to remember positive times without [-]*"), and the physical impact of loss-related memories (e.g., "*The memories of [-]'s death make my body ache with overwhelming fatigue*"). Four further items, taken from the Intrusions Questionnaire (13), asked about unintentional memories of the loss (frequency in the last week, distress, how much they seemed to be happening now instead of in the past, and the extent to which they felt as though they were reliving the memory).

Symptom Measures

Prolonged Grief Disorder

At the time this study was conceptualised no criteria for prolonged grief had officially been adopted by ICD-11 or DSM-5-TR. Therefore, data were collected using the 16 symptoms of persistent complex bereavement disorder (PCBD) (5). An extended version of the Prolonged Grief Disorder Scale (PG-13; Prigerson and Maciejewski (22) was used to assess the prevalence and severity of PCBD symptoms. Ten of the symptoms of the PGD criteria presented by Prigerson and colleagues (23) overlap with the symptoms of PCBD (e.g., yearning for the deceased, feelings of emotional numbness/detachment from others, feeling that a part of oneself died along with the deceased). Six additional items were added to the PG-13 items that correspond to the symptoms of the PCBD criteria not represented by the PGD-2009 criteria. Items were measured on a five-point scale with separation distress items rated (0–not at all to 4–at least once a day) and cognitive, emotional, and behavioural grief symptom items rated (0–not at all to 4–overwhelmingly).

The 10 symptom DSM-5-TR criteria can be fully represented with these items (3). For the ICD-11 criteria symptoms (4) we included item 14 from the PCL-5 "trouble experiencing positive feelings" rescaled to match the PG-13 items. All other criteria were covered by PCBD items with the exception of the intense emotional pain of blame symptom. In previous research this has been represented by items pertaining to self-blame (e.g., feelings of guilt) (24–26) therefore blame and guilt were represented by a single item (i.e., feeling bad about oneself because of things that happened in relation to the death or the relationship) (PGD ICD-11, cross-sectional α = 0.90, test-retest α = 0.89, longitudinal

$\alpha = 0.89$; PGD DSM-5-TR-11, cross-sectional $\alpha = 0.90$, test-retest $\alpha = 0.89$, longitudinal $\alpha = 0.90$).

Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5) (27). The PCL-5 is a self-report instrument assessing distress associated with the 20 symptoms of PTSD in DSM-5 over the past month. Items were rated on a five-point scale, from (0–not at all to 4–extremely). Internal consistency was excellent in all samples (cross-sectional $\alpha = 0.94$, test-retest $\alpha = 0.94$, longitudinal $\alpha = 0.94$).

Patient Health Questionnaire (PHQ-9) (28). The PHQ-9 is a self-report measure that mirrors the nine major depressive symptoms for major depressive disorder according to the Diagnostic and Statistical Manual, 4th Edition, Text Revision [DSM IV-TR (29)]. Each item is scored (0–not at all to 3–nearly every day) in the last two weeks. Internal consistency was excellent in all samples (cross-sectional $\alpha = 0.92$, test-retest $\alpha = 0.92$, longitudinal $\alpha = 0.91$).

The Oxford Grief Coping Strategies Scale—Proximity Seeking Subscale. This 23-item questionnaire asks participants on a 5-point scale (1–never to 5–always) to indicate how often they used particular strategies to cope with their loss. Items pertain to four content factors: Avoidance, Proximity seeking, Grief rumination, and Injustice rumination. The 7-item proximity seeking subscale measures the extent to which bereaved individuals engage in behaviours [e.g., "*I feel compelled to touch things that they touched (e.g., belongings, chairs, beds)*"], activities (e.g., "*I neglect other things because I spend a lot of time doing things for them [e.g., creating memorials, fundraising)*"] and experiences (e.g., "*I dwell on the things we won't get to do together*") aimed at restoring or maintaining proximity to the deceased person. Composite reliability was good in the cross-sectional sample ($\omega = 0.87$).

Statistical Analyses

Factorial Validity

Factor analyses were conducted using Mplus Version 8 (30). Cross-validation of the factorial model was conducted using a 50% random split of the first dataset (31). The initial measurement model was built using exploratory factor analysis (EFA) on one half of the data and then tested on the other half using confirmatory factor analysis (CFA). The estimation method employed in factor analysis is determined by the distribution of the variables in question. Recent advances in statistical software have meant that variables measured on different scales can be entered into the same model within an EFA and CFA framework using weighted least squares mean and variance adjusted (WLSMV) estimation (30). The OG-M comprises items rated on a 0 (not at all) to 4 (very strongly) with four items taken from the Intrusions Questionnaire (13) originally rated on a different scale, therefore, a WLSMV estimation was employed to handle items with mixed distributions. Geomin oblique rotation was used as scale factors were expected to correlate (30). Conceptual interpretability, eigenvalues greater than 1, a scree plot derived using parallel analysis (32, 33), and model fit statistics were used to determine model adequacy. A χ^2 goodness-of-fit test where the χ^2:df ratio is smaller than 3:1 was considered acceptable. A comparative fit index (CFI) or Tucker Lewis Index (TLI) of 0.90 or higher or 0.95 or higher was considered acceptable and good respectively. For root mean square error of approximation (RMSEA) 0.08 or lower was considered acceptable and 0.06 or lower was considered good (34–36). Decisions about factor determinacy were made based on (1) factor loadings greater than 0.35 and (2) items with comparable cross-loadings were ultimately placed on the factor where they loaded most strongly (37). Modification indices were only considered when large (>10) and in line with the conceptual interpretation (37).

Psychometric Validation

Composite reliability was assessed by McDonalds' Omega ($\omega = (\Sigma|\ \lambda i\ |)^2/([\Sigma|\ \lambda i\ |]^2 + \Sigma\delta ii)$, where λi are the factor loadings and δii, the error variances) for WLSMV on the total scale in the CFA (38). Criterion and convergent validity were determined using correlations with measures of psychopathology (i.e., PGD, PTSD, and depression) and behaviours of proximity seeking to the deceased [i.e., Oxford Grief Coping Strategies Scale (OG-CS)–Proximity Seeking subscale]. The stability of the total scale and subscales over time was measured using the test-retest reliability sample. A correlation greater than 0.70 between two time points a week apart was used to indicate acceptable retest reliability. The average variance extracted (AVE) score was calculated to determine the average variance in the latent factor that is accounted for by its items (39). A score of 0.50 or higher confirms factorial convergent validity (40).

Scale Reduction

Next, we aimed to create a clinician-version consisting of a shortened list of items from the original memory characteristics scale that balanced predictive validity with ease of use. The OG-M items were subject to Area Under the Curve (AUC) analysis of Receiver Operating Characteristics curves (ROC) (41). Each item was analysed for its ability to predict a diagnosis of PGD using the DSM-5-TR diagnostic criteria and ICD-11 criteria (3–5). Participants were considered as meeting criteria for ICD-11 PGD if their loss had occurred at least 6 months previously (12 months for DSM-5-TR) and they endorsed at least one item of separation distress daily, and at least 1 of 10 (3 of 8 for DSM-5-TR) symptoms of cognitive, emotional, and behavioural symptoms, resulting in significant impairment of functioning. The AUC indicates the probability that a participant selected at random with a diagnosis will score higher on the OG—M than a participant without a diagnosis (42). A value of above 0.90 is considered an excellent predictor of the outcome, with values above 0.80 reflecting good, and above 0.70 fair (43, 44).

Structural Equation Modelling

Finally, in order to determine the predictive role of memory characteristics on grief severity we employed a second-order autoregressive cross-lagged panel model in Mplus Version 8 (30). We present the results for both ICD-11 and DSM-5-TR criteria for PGD. Sum scores for the OG-M and PGD criteria at baseline (0–6 months), short-term follow up (6–12 months) and long-term follow-up (12–18 months) were calculated and autoregressive paths were modelled to account for the influence of variables at preceding time points. Correlated errors between memory characteristics and PGD symptoms at concurrent time points were also added to account for their joint fluctuation over time. Cross lagged paths estimated the extent to which memory characteristics predicted PGD symptoms at a later time point and vice versa after controlling for autoregressive paths and concurrent associations between symptoms and memory characteristics (see **Figures 1**, **2**).

A full information maximum likelihood (FIML) approach implemented in Mplus was used to estimate missing data to minimise the bias associated with attrition. A majority of participants completed the OG-M at all three time points (66.2%) with a high proportion answering at least two (87.6%); no participants were excluded. Covariance coverage, which measures the impact of missing data, ranged from 0.66 to 0.93 for each pair of variables, well above the minimum threshold of 0.10 for model convergence (45). The following fit indices were used to determine adequate fit: χ^2 $p > 0.05$, CFI > 0.90, TLI > 0.90, RMSEA < 0.01 (34–36).

RESULTS

Exploratory Factor Analyses—Loss-Related Memory Characteristics

All 27 items were entered into exploratory factor analyses using WLSMV estimation, which is recommended for outcomes with mixed distributions. Inspecting eigenvalues greater than 1 suggested a three-factor structure. The first factor accounted for a large proportion of the variance with an eigenvalue of 14.12, the two smaller factors had eigenvalues of 1.40 and 1.33, respectively. The scree plot suggested a two-factor solution. The one-factor model indicated a good fit to the data (CFI = 0.99, TLI = 0.98, RMSEA = 0.057 (0.05–0.06), χ^2 = 636.55 on df = 324, χ^2:df = 1.97). The two-factor solution fit statistics indicated a slightly worse fit to the data (CFI = 0.98, TLI = 0.98, RMSEA = 0.065 (0.06–0.07), χ^2 = 664.72 on df = 298, χ^2:df = 2.23) and the three-factor solution, while demonstrating the best fit (CFI = 0.99, TLI = 0.99, RMSEA = 0.051 (0.04–0.06), χ^2 = 480.51 on df = 273, χ^2:df = 1.76), was not conceptually interpretable. No items loaded strongly on the second factor and only one item loaded strongly on the third. The four-factor solution did not converge. Therefore, a one-factor solution was deemed to be the most appropriate fit for the data. Inspection of the modification indices suggested that a correlated error should be added between "*When I remember things we did together it feels like I am no longer the same person*" and "*When I remember something I did in the past; it feels like I am no longer the same person*" (*MI* = 47.89). These correlated errors are likely due to similar wording and as such it seems likely that some of the shared variance between these items can be attributed to item wording instead of the factor on which these items load (46).

Confirmatory Factor Analyses—Loss-Related Memory Characteristics

The CFA assessed the fit of the chosen one-factor solution with one correlated error using the CFA sample (N = 328). The fit statistics for the one-factor indicated a good fit CFI = 0.98 and TLI = 0.98, and a close to good fit for RMSEA = 0.062 (0.06–0.07), χ^2 = 678.35 on df = 323, χ^2:df = 2.10) supporting the chosen solution in the EFA. **Table 2** summarises the standardised factor loadings for the one-factor solution using EFA and CFA.

Psychometric Validation—Loss-Related Memory Characteristics

The total loss-related memories scale demonstrated excellent composite reliability (ω = 0.97) and sufficient convergent validity (AVE > 0.5). Test-retest reliability over 7 days for the OG-M was excellent (r = 0.90, $p < 0.001$). Correlations between the total score of the OG-M and symptom measures of PGD (ICD; r = 0.84, $p < 0.001$, DSM; r = 0.82, $p < 0.001$), PTSD (r = 0.77, $p < 0.001$), depression (r = 0.65, $p < 0.001$), and behavioural proximity seeking (r = 0.70, $p < 0.001$) were all strong and significant, confirming criterion validity. **Table 3** summarises the psychometric validation of the OG-M.

The Oxford Grief–Memory Characteristics–Short Scale

Balancing overlapping content and AUC statistics calculated on the larger cross-sectional sample 1 (N = 676), 11 items were removed from the OG-M to create the Oxford Grief–Memory Characteristics–Short Scale (OG-M-S) (**Table 4**). Two of the removed items ("The memories of [-]'s death make my body ache with overwhelming fatigue" and "When I remember things we did together it feels like I am no longer the same person") had AUC values higher than some of the retained items. However, these two items were deemed to overlap in content (i.e., visceral experiences and memories triggering identity disruption) with items scoring higher on AUC and were, therefore, removed for parsimony. The total OG-M-S had an AUC of 0.85 (*SE* = 0.02, $p < 0.001$, *CI* = 0.82–0.88) for PGD ICD-11 and 0.80 (*SE* = 0.02, $p < 0.001$, *CI* = 0.77–0.84) for PGD DSM-5-TR which was comparable with the full OG-M ICD-11; AUC = 0.84 (*SE* = 0.02, *CI* = 0.81–0.87); DSM; AUC = 0.80 (*SE* = 0.02, *CI* = 0.76–0.83). Converting the AUC to Cohen's d using the formulas described in Ruscio (47) gives a very large effect size for both the full and the short OG-M scale (ICD-11; d = 1.47, DSM-5-TR d = 1.19) in the prediction of PGD (48).

Psychometric and Factorial Validity of the Oxford Grief–Memory Characteristics–Short Scale

Exploratory factor analysis of the shortened scale revealed one eigenvalue above 1 (9.09). The one factor solution was a good fit

TABLE 2 | Analyses of the Oxford Grief loss-related memory characteristics scale (OG-M).

		Factor	
		1	
Loss-related memories items		**EFA**	**CFA**
1	In the last week, approximately how often did unwanted memories of the loss pop into your mind?	0.70	0.65
2	How distressing were these memories?	0.84	0.81
3	To what extent did they seem to be happening now instead of being something from the past?	0.73	0.78
4	To what extent were you reliving your experience from the loss?	0.87	0.86
5	The memories of [-]'s death make my body ache with overwhelming fatigue.	0.80	0.81
6	The physical pain of loss is something I carry everywhere.	0.85	0.84
7	When I remember the loss it feels unreal.	0.72	0.58
8	Seeing other people with their partners or families makes me painfully aware of my loss.	0.68	0.65
9	Many different things trigger distressing memories of the loss.	0.84	0.83
10	If my mind is distracted from my grief for a while it will hit me like a wave later.	0.81	0.80
11	I am reminded of the loss for no apparent reason.	0.77	0.69
12	When I remember the loss, I feel the same emotions I felt at the time.	0.64	0.70
13	When I try to remember good times we have shared, memories of the loss pop up.	0.69	0.74
14	The loss feels as if part of my body is missing.	0.80	0.80
15	Many things in everyday life trigger overwhelming sadness.	0.83	0.80
16	When I think of [-] all I can remember is their suffering.	0.57	0.54
17	When I think about [-] I will always think about how they died.	0.62	0.60
18	My memories of [-] are so vivid it feels like they are here.	0.47	0.43
19	When I remember things we did together it feels like I am no longer the same person.	0.82	0.67
20	Memories of things we did together are painful.	0.72	0.67
21	Even nice memories cause me to feel significant pain.	0.84	0.77
22	I struggle to remember positive times without [-].	0.66	0.64
23	Looking at a calendar mainly reminds me of the bad things that happened on those days.	0.58	0.68
24	When I remember something I did in the past; it feels like I am no longer the same person.	0.79	0.65
25	I hardly remember anything that I did without [-].	0.69	0.55
26	I feel a strong urge to comfort [-].	0.60	0.67
27	I find myself suddenly overcome to find [-].	0.66	0.67

EFA (N = 348) CFA (N = 328). Factor labelled as Loss-Related Memory Characteristics. All factor loadings significant to p < 0.05.

to the data $\chi^2 = 225.87$ on $df = 104$, $\chi^2{:}df = 2.17$, CFI = 0.99, TLI = 0.99, RMSEA = 0.059 (0.05–0.07). The two-factor solution had a marginally better fit $\chi^2 = 179.45$ on $df = 89$, $\chi^2{:}df = 2.01$, CFI = 0.99, TLI = 0.99, RMSEA = 0.055 (0.03–0.06), but was not optimal because only two items loaded strongly on the first factor. Confirmatory factor analysis of the one factor solution resulted in a good fit CFI = 0.99, TLI = 0.99, $\chi^2 = 200.32$ on $df = 104$, $\chi^2{:}df = 1.92$, RMSEA = 0.055 (0.04–0.07)[1].

TABLE 3 | Psychometric validity of the OG-Loss-related memory characteristics scale.

Reliability/Validity	Measure	Total scale
Composite	McDonald's Omega	0.96
Criterion	PGD ICD *r*	0.84***
	PGD DSM	82***
	PTSD *r*	0.77***
	Depression *r*	0.65***
	Proximity seeking (OG-CS) *r*	0.70***
Test-retest	*r*	0.90***
Convergent	AVE	0.50

*Test-retest reliability confirmed if r > 0.70. Convergent validity of factors confirmed if AVE > 0.5. r, correlation; AVE, Average variance extracted. ***p < 0.001.*

The shortened scale had excellent composite reliability $\omega = 0.97$ and good test-re-test reliability $r = 0.87$. Criterion validity correlations with the symptom scales were all strong and significant (PGD: ICD, $r = 0.84$; DSM, $r = 0.84$; PTSD, $r = 0.76$; depression, $r = 0.65$; proximity seeking, $r = 0.69$). The scale also met the requirements of convergent validity AVE = 0.67.

Cross-Lagged Models of the Oxford Grief–Memory Characteristics Scale

Both the PGD ICD-11 and the PGD DSM-5-T5 cross-lagged models were an excellent fit to the data (ICD, $\chi^2 = 1.47$, $df = 2$, $p > 0.05$, RMSEA = 0.00 (0.00–0.11), CFI = 1.00, TLI = 1.00; DSM, $\chi^2 = 5.12$, $df = 2$, $p > 0.05$, RMSEA = 0.075 (0.00–0.16), CFI = 1.00 TLI = 0.98). Parameter estimates are

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[1] See **Supplementary Material** for EFA and CFA factor loadings of the OG-M-S.

TABLE 4 | Area under the curve analysis of the OG-M items.

Loss-related memory characteristics items—Shortened scale and removed items		ICD AUC	DSM AUC
1	In the last week, approximately how often did unwanted memories of the loss pop into your mind?	0.77	0.75
2	How distressing were these memories?	0.76	0.74
3	To what extent were you reliving your experience of the loss?	0.77	0.73
4	The physical pain of loss is something I carry everywhere.	0.79	0.75
5	When I remember the loss it feels unreal.	0.70	0.67
6	Seeing other people with their partners or families makes me painfully aware of my loss.	0.70	0.67
7	Many different things trigger distressing memories of the loss.	0.76	0.71
8	If my mind is distracted from my grief for a while it will hit me like a wave later.	0.78	0.72
9	When I remember the loss, I feel the same emotions I felt at the time.	0.70	0.67
10	When I try to remember good times we have shared, memories of the loss pop up.	0.72	0.67
11	The loss feels as if part of my body is missing.	0.80	0.77
12	Many things in everyday life trigger overwhelming sadness.	0.78	0.74
13	Even nice memories cause me to feel significant pain.	0.75	0.71
14	When I remember something I did in the past; it feels like I am no longer the same person.	0.77	0.77
15	I feel a strong urge to comfort [-].	0.70	0.67
16	I struggle to remember positive times without [-].	0.73	0.69
R	When I think about [-] I will always think about how they died.	0.69	0.67
R	To what extent did they seem to be happening now instead of being something from the past?	0.70	0.65
R	The memories of [-]'s death make my body ache with overwhelming fatigue.	0.78	0.72
R	I am reminded of the loss for no apparent reason.	0.73	0.68
R	When I think of [-] all I can remember is their suffering.	0.65	0.62
R	My memories of [-] are so vivid it feels like they are here.	0.62	0.60
R	When I remember things we did together it feels like I am no longer the same person.	0.77	0.75
R	Memories of things we did together are painful.	0.73	0.69
R	Looking at a calendar mainly reminds me of the bad things that happened on those days.	0.67	0.67
R	I hardly remember anything that I did without [-].	0.71	0.69
R	I find myself suddenly overcome to find [-].	0.67	0.65

AUC, Area Under the Curve; R, Removed item.

presented for PGD ICD-11 in **Figure 1** and PGD DSM-5-TR in **Figure 2**. For both PGD conceptualisations, memory characteristics predicted PGD symptoms 6 months later after controlling for autoregressions and correlated errors between concurrent symptom and memory characteristics. This effect can be observed from baseline (0–6 months) to short-term follow-up (6–12 months), as well as from short-term to long-term follow-up (12–18 months). In contrast, while PGD symptoms significantly

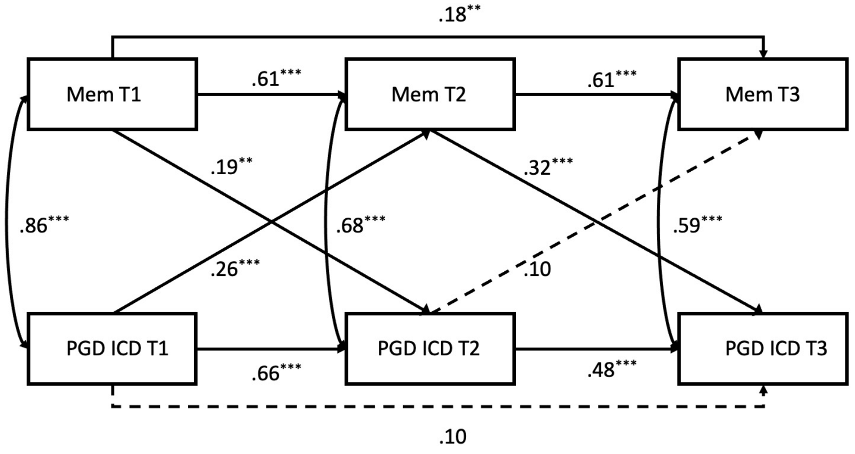

FIGURE 1 | Autoregressive cross-lagged model of PGD ICD-11 and loss-related memory characteristics. Standardised coefficients are shown. Broken lines indicate non-significant paths. MEM, The Oxford Grief Memory Characteristics Scale (OG-M); PGD ICD, Prolonged Grief Disorder according to the ICD-11 diagnostic criteria. Asterisks indicate significant associations (**$p < 0.01$, ***$p < 0.001$). $\chi^2 = 1.47$, *df* = 2, $p > 0.05$, RMSEA = 0.00, CFI = 1.00, TLI = 1.00.

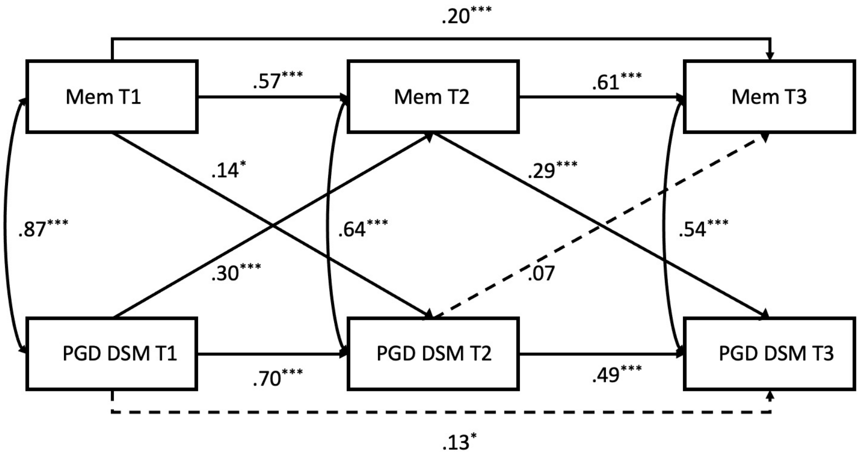

FIGURE 2 | Autoregressive cross-lagged model of PGD DSM5-TR and loss-related memory characteristics. Standardised coefficients are shown. Broken lines indicate non-significant paths. MEM, The Oxford Grief Memory Characteristics Scale (OG-M); PGD DSM, Prolonged Grief Disorder according to the DSM-5-TR diagnostic criteria. Asterisks indicate significant associations ($^{**}p < 0.01$, $^{***}p < 0.001$). $\chi^2 = 5.12$, $df = 2$, $p > 0.05$, RMSEA = 0.075, CFI = 1.00 TLI = 0.98.

predicted future memory characteristics between baseline and short-term follow-up, this effect was not evident during the long-term follow-up. The results of the memory characteristics short scale (OG-M-S) did not differ from the full OG-M[2].

DISCUSSION

The aim of this study was to test the psychometric and factorial properties of the Oxford Grief–Memory Characteristics scales (OG-M and OG-M-S). It was designed to measure the content, triggers, qualities, and consequences of loss-related memories and was developed from interviews with bereaved individuals with and without a diagnosis of PGD (19). Exploratory and confirmatory factor analyses supported a unidimensional solution. Psychometrics indicated the scale had excellent composite and test-retest reliability, criterion validity, and adequate convergent validity. A shortened version of the OG-M, suitable for use in clinical settings, demonstrated good to excellent psychometric and factorial validity. Longitudinal cross-lagged analyses of the memory characteristics scale revealed it as a significant predictor of future symptoms of PGD for both ICD-11 and DSM-5-TR criteria after controlling for the effect of prior symptoms levels and concurrent associations. These results are supported by a previous finding that the OG-M was able to distinguish between trajectories of high and low grief over time (49).

An important finding was that while early memory characteristics and PGD symptoms (0–6 months) showed significant cross-lagged relationships, each measure at baseline predicting the other 6 months later (short-term follow-up), only memory characteristics at 6–12 months predicted the long-term maintenance of PGD symptoms at 12–18 months, whereas symptom severity at 6–12 months no longer predicted memory characteristics at long-term follow-up. This pattern of results would be expected by psychological models of PGD (6, 8) that aim to explain the persistence of grief symptoms beyond the initial months of grieving, where most people will have frequent memories of the death and the deceased together with feelings of loss and grief. People for whom grief does not resolve naturally are thought to differ from those who adapt to their loss by several factors that maintain their symptoms, including memory characteristics, appraisals, social disconnection and unhelpful coping strategies (49–53, 67).

Factor analyses suggested that the memory characteristics measured with the OG-M are explained by one underlying dimension. This could be partly because the sample included a wide range of bereaved people with a wide range in severity of their grief reactions and endorsement of the memory items. It is possible that in a clinical sample of patients with PGD, factor analyses would reveal a more complex factor structure. However, it is also possible that a unidimensional factor structure would be retained as the items of the OG-M can be interpreted as representing different aspects of memory “re-experiencing” driven by poor loss memory integration.

Previous work has suggested that traumatic memories, including traumatic loss memories, that are poorly integrated with other information in autobiographical memory are easily triggered due to poor inhibition of cue-driven retrieval. As a result, varied sensory information that has similarities with the traumatic situation has the ability to trigger intrusive trauma memories that appear to happen in the present (10, 11). Further work concluded that integrating information relevant to the worst moments of the trauma, which may not have been available to or accessed by the individual at the time, into the memory was central to effective memory updating and to change the highly personal threatening meanings of the traumatic moment (54). For example, for a client with PTSD who during a physical assault thought they were going to die and their family would not be provided for, updating the relevant moment in memory

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[2] See **Supplementary Material** for results of cross-lagged analyses of short scale.

with information only apparent after the trauma such as "I did not die, I am still providing for my family" subsequently reduced the threatening meaning and distress, and led to a reduction in intrusive trauma memories (55). With grief-related memories, updating focuses on the personal meaning of the death for the client and also the meaning of the cherished person to them. Here a memory of seeing the dying person on the day before their death may be reexperienced along with meanings such as "they are suffering unbearable pain and feel let down," creating a sense that the death is happening again or has just happened. This feeling of "nowness" of the memories maintains a sense that the person is still suffering and contradicts the permanence of the death. Here aspects of the death that bring comfort and contradict the meanings such as "He did die but he was not alone, a nurse was with him, and he is no longer suffering" decreases distress, facilitates the acceptance that the death is in the past, and leads to a reduction in memories of seeing the person in distress [see Ehlers and Wild (56)].

Another potential indicator of the failure to process loss memories as permanent and final measured by the OG-M is the intrusive desire to both search for and comfort the deceased (57). Such intrusions are hypothesised to arise due to activation of the attachment in the absence of the deceased, which instigates a "search effort" aimed at re-establishing physical or psychological proximity (58, 59), a relationship that was supported by the strong positive correlation of the memory scales with proximity seeking behaviours. While initially the loss is not fully conceived as permanent resulting in the searching described here, Horowitz (60) and others have hypothesised that only through emotional tolerance of repeated attempts at reunion does a revised understanding of the loss as irrevocable develop. Clinical approaches that have evolved from this understanding have focused on facilitating an internalised psychological connection to the deceased to act as a "secure base" in the absence of physical proximity (61). Techniques such as imaginal conversations with the deceased (62) and restorative retelling in which the bereaved person imaginally comforts their dying loved one in a way that was denied to them in the actual circumstance (63) have been reported as helpful.

The OG-M and OG-M-S provide a comprehensive research and clinical tool for measuring aspects of loss memories relevant to poor loss memory integration. However, there are some limitations that should be considered. The study used online self-report measures to measure psychopathology making the probable diagnoses reported here less reliable than formal clinical interviews. Also previous research has suggested that self- report measures may overestimate the prevalence of mental health problems (64). Therefore, future research investigating memory characteristics in severe and enduring grief would benefit from utilising a sample diagnosed via clinical interviews to better understand the role of the OG-M in predicting psychopathology. The measurement of PGD according to ICD-11 criteria was approximated using items derived from other validated measures of PGD and PTSD, and as such we cannot fully rule out some measurement error. However, reliability of these items was good or excellent in all samples. Future research able to more closely measure ICD-11 criteria, including the item related to blame, should be conducted to ensure the generalisability of the findings. Finally, the sample employed here were largely female and Caucasian. With recent research demonstrating a wide variation of PGD prevalence across cultures (65, 66) it will be important to replicate this work in more diverse populations to ensure the cultural relevance of loss memory characteristics.

Despite these limitations, this study presents the comprehensive OG-M and shortened OG-M-S questionnaires for the assessment of loss-related memory characteristics after bereavement and demonstrates their capacity to serve as metrics for poor loss memory integration relevant to the development and maintenance of PGD and importantly, its treatment.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because no data arising from this study can be shared publicly in line with the terms of the ethics agreement provided by the University of Oxford Medical Sciences Inter-Divisional Research Ethics Committee (MS-IDREC-C1-2015-230 and MS-IDREC-C1-2015-231), which stipulated that no data could be shared with anyone outside of the research team. The relevant ethics board can be contacted on ethics@medsci.ox.ac.uk. Readers can request analyses scripts and corresponding outputs from the Centre for Anxiety Disorders and Trauma at the University of Oxford, The Old Rectory, Paradise Square, Oxford, OX1 1TW. Email: oxcadat.enquiries@psy.ox.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the University of Oxford Medical Sciences Inter-Divisional Research Ethics Committee (MS-IDREC-C1-2015-230 and MS-IDREC-C1-2015-231). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KS and AE developed the study concept and design. KS performed the data collection and statistical analysis under the supervision of AE. KS drafted the manuscript. AE and JW provided the critical revisions. All authors contributed to the questionnaire development.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.814171/full#supplementary-material

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Dreading Yet Hoping: Traumatic Loss Impacted by Reference DNA Sample Collection for Families of Missing People

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The trauma of having a family member missing is commonly described as an ambiguous loss where the finality of the loss is not realized, as is experienced with a death. There is uncertainty due to the trauma of the absence and subsequent police investigation, leading to physical and emotional impacts for the aftercare of those left behind. There are 850 unidentified human remains and 2,600 long-term missing persons cases in Australia. The Australian Federal Police (AFP) National DNA Program for Unidentified and Missing Persons aims to scientifically link these cases using modern DNA techniques and databases. A DNA-led identification effort may assist to provide answers to Australian families searching for missing relatives, but may also contribute to the trauma experienced by these families. A literature review demonstrated empirical research for the development of scientific best practices for the collection of reference DNA samples for forensic purposes, but minimal evidence about the impact of reference DNA sample collection on kin when attempting to identify the deceased remains of missing people in non-mass casualty situations. The aim of this study was to develop an academically robust understanding of the unique impact of reference DNA sample collection on families of missing persons and support pathways tailored to the experience. This study involved 26 Australian families of long-term missing (ranging from 1 to 20+ years) people in Australia anonymously completing a mixed-methods online survey about their experiences of providing reference DNA samples to aid missing persons investigations. Respondents were representative of a range of ages, genders and relationships to the missing individual. The thematic analysis of the survey results identified the provision of a reference DNA sample: (1) resembles an overt act of hope as families perceive their sample assists the investigation, whilst also being traumatic, triggered by the prospect of scientifically matching their missing family member to a set of unknown human remains; (2) can cause immediate interpersonal impacts and ongoing impacts to families' wellbeing; and (3) can be improved by considering the environment where the sample is collected, professionalism of the police officer collecting the sample, timeliness of the

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provision of the sample, level of support provided during and after sample collection, and effective communication of forensic procedures and processes as they relate to the missing persons investigation. The study concludes that the complexity associated with provision of family reference samples requires the development and implementation of best practice guidelines, including psycho-education strategies to be used by practitioners to minimize the vicarious trauma for relatives already traumatized by the loss of their missing family member. These guidelines would support the objectives of the AFP Program and benefit all routine missing persons investigations.

Keywords: missing persons, DNA sample, traumatic loss, unresolved grief, ambiguous loss, unidentified human remains

INTRODUCTION

In Australia, a missing person is defined as a person whose whereabouts are unknown and there are concerns for their safety and wellbeing. Recent research from the Australian Institute of Criminology (1) note that people go missing for various reasons, including complex mental health conditions, concerns regarding suicidality, they are victims of crime or they are young people seeking independence. Every year in Australia, more than 40,000 reports are made in relation to a missing person (1). Those who are reported missing are likely to return within 1 month, with long-term missing people (defined as missing for longer than 3 months) accounting for 2,600 Australians at present. A nation-wide audit led by the Australian Federal Police (AFP) National DNA Program for Unidentified and Missing Persons (AFP Program) has recently recorded 850 unidentified humans remain in Australia; a higher figure than initial estimates of 500 (2, 3). The expectation is that some of these unknown remains will be linked to known missing persons, who in some cases have been absent for decades (3). To achieve this, the AFP Program will use modern DNA techniques and databases to match the DNA from unknown deceased persons to DNA volunteered by missing person relatives on a national level for the first time in Australia.

When unidentified human remains are recovered, the process of DNA profiling and matching has been shown to provide scientific support regarding the unknown deceased person's identity following large-scale disasters (4, 5). A review of the literature identified that there is empirical research regarding the optimal process of reference DNA sample collection for forensic purposes, including recommendations for the specific type and number of reference DNA samples that should be collected from biological relatives of a missing person or disaster victim (3, 6). Additionally, there are recently published international guidelines for police and forensic investigators regarding the use of DNA for humanitarian and mass disaster operations (7–9), and publicly available information brochures [e.g., (10)] and online resources (e.g., https://www.missingpersons.gov.au/support/national-dna-program-unidentified-and-missing-persons) for families to aid their understanding of the use of DNA for identifying human remains. However, there is minimal evidence, and therefore consideration, of the impact of reference DNA sample collection on kin when attempting to identify the remains of unknown deceased persons for domestic missing persons cases (i.e., non-mass casualty events).

The trauma of having a family member missing is commonly described as an ambiguous loss (11, 12), where the finality of the loss is not realized and families exist in the liminal space between the person being "both here and gone" (13, 14). The care required after the loss is different to a death where there is uncertainty for those left behind where they can be physically and emotionally impacted (15). This liminality is identified by time periods where ideas of uncertainty are "played out" by family members where the potential for return is viewed alongside ideas of never returning (16). The experience of being "left behind" when someone is missing is viewed as a traumatic event characterized by reactions of waiting and loss of control, irrespective of the length of time the person is missing (17). Research identifies that the longer-term impact of having someone missing does not present like grief and loss reactions, where the loss is able to be managed over time (18). Ambiguous loss, where the person remains missing, can exist for decades given families do not have the necessary information to be able to state with certainty that a person will or will not come home, in addition to thoughts about being alive or deceased (14).

Parker and colleagues (19), reflecting on the ethical impacts of using DNA to identify human remains, note that DNA identification has both social and individual goals. The humanitarian goal to confirm who a person is, offers families awaiting news about the traumatic loss of a missing person the chance to perform funerary rights. This in turn provides psychosocial benefits to families waiting for information. Parker and colleagues (19) also highlight that the psychological impact of a traumatic event, such as having a person you love go missing, can be compounded by the social isolation that occurs due to lack of certainty, resulting in psychological pain. Identification of an individual can address feelings of exclusion because they offer certainty that, socially, is likely to be accepted by the community. The disenfranchised grief, as noted by Doka (20), of having someone missing can be resolved by certainty as to their whereabouts with an ambiguous or "non death related" (pg. 7) loss being non-linear, creating no clear trajectory as to how people may move away from their loss given its unresolved nature. In addition to Doka's work (20), Boss (13, 14) notes that families left behind can be frozen in time, in response to their grief, where the situation is locked to the time the person vanished or to the lack of information required to accept the loss.

Research in this space is focused on the experiences of families with family members unaccounted for following mass casualty events. As an example, the human rights organization "Abuelas de Plaza de Mayo", which was formed by the grandmothers of the Plaza de Mayo in response to the many families still searching for loved ones missing since the last Argentinian dictatorship from 1976 to 1983 [see (21)], have published real-time observations of continuing to search for the missing and the impact of forensic processes. The remainder of the literature also relates to identity formation in the sense of people being able to understand who they are and where they belong, as a result of the use of reference DNA samples, for those disconnected from family due to armed conflict, political unrest, or natural and man-made mass disasters (22, 23). This literature provides context to awareness regarding the impact of searching for previous generations who are presumed deceased (24), but not to present day searching for long-term missing people.

Provision of a reference DNA sample may be an overt act of hope for some families by being able to provide information to help the investigation, or it may be a traumatic event that signifies that identification of human remains cannot be conducted visually, and requires the undertaking of scientific matching processes due to the condition of the remains and/or the procedural requirements of the jurisdiction. In 2015, the INTERPOL DNA monitoring expert group [see (9)] noted that there was a need for both national and international cooperation in missing persons investigations because "families have a fundamental right to know, and the right to justice" (pg. 2). Unlike DNA identification of disaster victims, which are typically identified rapidly due to the high profile and public nature of the event, community expectations and provision of adequate resources, DNA identification may take an extended period of time for routine missing persons cases (25). This has previously been reported to be the case in Australia, despite advances in DNA technology and databases over the last decade. This paper reflects on ways to ensure that the lived experience of families of missing people can be considered as part of the development of national best practices for missing persons investigations being undertaken as an objective of the AFP Program.

The impact of provision of a reference DNA sample, from the perspective of those providing the sample, has not yet been researched despite the practice becoming common when working with families of long-term missing people, as noted in standard operating procedures prepared for law enforcement and related agencies [e.g., The SOS Guide, National Missing Persons Coordination Centre, n.d., see (26)]. The aim of this qualitative study was to investigate how, as potentially traumatized individuals, families of missing people negotiate the process of providing a reference DNA sample by reflecting on the impact of that sample on their loss journey. We hypothesized that there is minimal awareness of the emotional toll on those relatives providing a family reference sample during a missing persons investigation, with the focus being on the procedural requirements. The aim of this study was to provide a platform for the perspectives of those with lived experience to be considered in the development of best practice family reference sample collection guidelines, given their current absence from the academic literature and policy making processes.

MATERIALS AND METHODS

Respondents

The sample was composed of 26 consenting adults (aged over 18 years) who self-identified as family members of a long-term missing person based in Australia (noting that the person could be missing in Australia or in another jurisdiction). Participants were asked to complete an anonymous survey shared as a live URL or QR code from June to November 2021.

The online survey was circulated via social media through a dedicated research page on Facebook, in addition to the social media pages of peak Australian organizations working with families of missing people to reduce selection bias. The Facebook page provided anonymity and ethical assurances to family members who wished to participate; either regarding safety of their responses in terms of how they are treated by the research team or for those who wanted to engage externally to their connection with Police. People who may have criminogenic histories, have an insecure relationship with police due to historical trauma or political interventions, as well as those that are ethically opposed to provision of a DNA sample, were able to share their perspectives to shape the evidence base (27). The use of an online survey allowed respondents to complete the survey at a time and in a place of their choosing. Respondents were assured that their reference DNA sample would not be linked to their survey responses given the anonymous nature of the data collection and that the processing of their reference DNA sample was independent to their decision to participate in some or all components of this study. Given the study was heavily reliant on qualitative data, collection matters of statistical or power issues were not relevant.

Data Collection and Data Analysis

The study utilized a mixed-methods online survey (see Appendix A) involving basic demographic characteristics of the respondent and open-ended questions using a descriptive analysis technique (28). Using both quantitative (closed-ended) and qualitative (open-ended) data, and then combining the two, the research team was able to answer their enquiry about the impact of reference DNA sample collection on families of missing people.

The analysis was informed by Braun and Clarke's (29) exploration of reflective thematic analysis, that the lead researcher is proficient in using across missing persons and suicide prevention projects. Saturation of themes was used to determine if there was adequate data to ensure the research question could be answered, and if the responses provided rich narratives to better understand the participant's lived experiences. The focus was to explore the learnt experience, coupled with the shared lived experience of being the family member of a missing person, to better understand how their stories are told and how they are perceived to be interpreted. The survey also sought to identify how families can be better supported in the future, to inform the development of best practices for the collection of family reference samples. Consensus of themes was achieved via recursive practice between the research team to ensure accuracy (30). The goal was to develop an academically robust understanding of the unique impact the collection of a reference DNA sample has on family members when a loved one is missing and to understand support pathways that are tailored to the experience.

Survey transcripts were analyzed independently by two coders using both an inductive and deductive approach similar to that described in Azungah (31). Preliminary analysis of each individual response was conducted as the data were collected. An audit trail of the analytic logic employed by the research team was maintained throughout data collection and analysis (32).

Data from each response were deductively coded against the study aims and data outlying to the aims were inductively coded to ensure that other experiences shared by respondents were not lost. Minor categories within each response were identified. During the second layer of coding, related or contrasting categories across responses were grouped. Outlying categories were not forced to fit into these groupings nor removed from analysis until their relevance was determined at a later stage. A third layer of coding identified minor themes across the categories, which was followed by the grouping of these into major themes. All categories and themes were tested among the research team at all stages of the analytic process for confirmability and dependability (32).

RESULTS

Respondent Characteristics

Anonymous survey data identified basic demographics (e.g., age, gender, location, status of missing persons case, cultural background and awareness of DNA procedures), followed by responses to short answer questions regarding their lived experience regarding decision making, experience of provision of a reference DNA sample, and emotional response to the sampling process.

Of the 26 respondents, more than half (15 respondents) represented parents or siblings of the missing person, and the timeframe for relatives being missing ranged from 1 to 5 years (12 respondents) to more than 20 years in some cases (3 respondents). The respondents' self-declared ages spanned from between 20 and 30 years (2 respondents) to over 70 (5 respondents), with a higher representation of respondents identifying as female (18 respondents). In terms of their knowledge about how DNA can assist a missing persons investigation, more than half of the respondents felt somewhat (8 respondents) or completely (7 respondents) confident about their understanding of the process.

Thematic Analysis

From the analysis of the qualitative data provided by the 26 respondents, three major themes were identified inductively. Respondent demographics are not recorded next to quotes to ensure privacy and minimize reidentification, however the relationship to the absent person and length of time missing are noted.

Theme 1: Uncovering Potential Trauma Associated With Provision of a Reference DNA Sample

The identification of the liminal space between the acceptance that a loved one was missing and concern for the potential finality of the unidentified human remains being confirmed as their missing person was revealed in some of the long text responses provided:

> *"It's sobering to think of my loved one being deceased and in a state of decomposition."* (Sibling of a person missing for more than 10 years.)
>
> "*DNA (matching) means there is no hope he is alive. I carry both hope and fear.*" (Sibling of a person missing for more than 5 years.)
>
> *"It's sad that this is required to identify him."* (Mother of a person missing for between 1 and 5 years.)
>
> *"I was both dreading and hoping that it would lead to a match, as well as hoping for peace of mind that it meant he couldn't/wouldn't be one of those cases we've all heard about where remains are left unidentified for years and years."* (Sibling of a person missing for more than 5 years; located deceased.)

Within this thematic analysis, the respondents also noted that the provision of the reference DNA sample may suggest the implication, to others, that their missing relative is deceased; an external sign of diminished hope created guilt by suggesting they were, as described by one respondent as "*not hopeful*":

> *"I want the match to be made AND I hope the match won't be made."* (Sibling of a person missing for <1 year.)

This theme also identified a sub-theme focusing on what was described as *"the active step"* of providing a reference DNA sample. This active, rather than passive, step offered self-described power, in a traditionally disempowered space that occurs when waiting for news. Families referred to providing a reference DNA sample, even without information as to how long a resolution may take, as allowing them to "*seek (potential) closure*", noting that:

> "*DNA could be the key one day, to finally bring him home.*" (Mother of a person missing for between 1 and 5 years.)
>
> *"The notion that this task of providing DNA might get us out of our stuckness was important and empowering. It was something I could actually do after much of the 'doing' – namely searching – had been exhausted)."* (Sibling of a person missing for 5 years and then located deceased.)
>
> *"It made it very real. It made us think about and be open to the idea the he could be deceased which is really hard because you are always hoping that they are still alive. It also provided hope and the feeling that we were doing something proactive."* (Sibling of a person missing for 7 years and then located deceased 4 years ago.)

Respondents were also capable, in the midst of exposure to potential trauma, to separate the action and focus on the scientific advancements; "*I'm happy to see technology developing*" explained the father of a son missing for more than 10 years. Similarly, a mother with a son missing for more than 5 years reflected "*at least if it's a body/skeleton/unknown person behind the scenes (it means) I have a glimmer of hope to find my son*".

Providing a reference DNA sample also provided a forward motion for families, as noted by a father of a missing person absent for 20 years; "*I looked at the process as a way of moving forward in an attempt to find out what happened to our son*". This was similar to other respondents who noted that the active, rather than passive, waiting for news offered by the capacity to provide a reference DNA sample for comparison; specifically, "*it made me feel like something was happening; like having it done might get us one step closer to resolution*".

For some respondents the act of providing a reference DNA sample was viewed through a procedural lens, where ideas about the emotional impact were held over, for the future:

> *"The only emotional aspect that has regularly come to mind is the future turmoil every time human remains are found - that always has and always will be the hardest part of this process for me."* (Mother of a person missing for 10 years.)

For others, there was the intertwining as to what a DNA match might mean in terms of what happened to their loved one:

> *"You start to think of different possible scenarios and your conflicting hope that you do find them but not by connecting DNA samples because that means they have passed. You want to know what's happened but you don't want that to be the outcome."* (Father of a person missing for more than 10 years.)

Theme 2: Practicalities and Procedures When Providing a Reference DNA Sample

Survey respondents reflected that the emotional impact of the process of providing a reference DNA sample was undeniable, as evidenced by the qualitative exemplar quotes from theme one. The respondents suggested that their engagement and interactions with police were at times positive, despite the reports of traumatic loss. In the survey, respondents were asked to rate their experience of the reference DNA sample collection process using a scale (positive, neutral or negative), prior to completing their free text responses. Only one respondent recorded a negative experience, with the remainder noting either a positive or neutral experience, despite the richness of the narratives about the traumatic impact.

From a procedural perspective, the recording of positive or neutral responses reflected the families' belief that police made them feel safe and supported during the reference DNA sample collection process. Narrative responses referred to individual behaviors of police, who demonstrated compassionate responses and gratitude for the family's contribution to the missing persons investigation. However, these reflections were outweighed by those family members who felt their reference DNA sample provision required better management. The sub-themes of the qualitative responses identified issues relating to the environment where the sample was collected, professionalism of the police officer collecting the sample, timeliness of the provision of the sample, level of support provided during and after sample collection, and knowledge and communication of forensic procedures and processes as they relate to the missing persons investigation.

Environment

Respondents noted that samples were taken in their home, in their workplace or at a police station; with many families finding attending police stations or police attending workplaces stressful or fostered a clinical experience.

> *"The environment was sterile, and unfamiliar (police headquarters), without any space to acknowledge the gravity of the situation. It was very transactional."* (Sibling of a person missing for 5 years and then located deceased.)

Another family member (parent of a person missing for more than 20 years) provided a sample in their workplace and felt this was "*insensitive*", with the officer "*treating it as if it was routine*".

Police Professionalism

Respondents reflected on the ways in which they encountered the police officer tasked with collecting the sample, and the way this impacted their distress:

> "*(Families) have already run all the possible scenarios through their heads 1000 times over but not let themselves believe the worst. So, they need sensitivity and understanding because this is a real person and this is real life. No one could ever understand what it feels like unless they have been through it.*" (Sibling of a person missing for more than 20 years.)

Respondents identified that it appeared as though some police officers had limited understanding of DNA identification procedures or these were unable to be effectively communicated to all family members, which enhanced feelings of uncertainty and left families unsupported. For example, "*one police officer has no true understanding of the process for missing persons, and how families might feel*" explained the mother of a missing child, absent for more than 5 years.

The ability of the police officers collecting the sample to satisfactorily answer questions about the storage of the sample, the legalities of what their DNA could be used for and the scientific approach used for human remains identification was an important step to make families feel emotionally safe during the process.

Timing

Long-term missing persons investigations, as identified by the respondents, were subject to changing procedures from police, during the months, years or decades since a disappearance. Respondents noted that the request for family members to provide a reference DNA sample had been conducted in an ad-hoc way in the past. This was often dependent on the purported circumstances as to why or how a person vanished (i.e., identifying if the absence was self-motivated or related to being a victim of a crime) or how long the person had been absent for.

Respondents noted that decisions regarding a request to kin for a reference DNA sample was either made via the investigating police officers, a Coronial enquiry into an absence or families proactively approached police as a way to ensure that every action had been undertaken to assist with seeking finality. The sibling of a person missing for 5 years noted:

> "*I can't stress enough how important I feel it is that samples are collected in the early stages of a disappearance, not solely from an administrative perspective, but so that loved ones aren't providing samples after the fact (as per what happened with my parent after his remains were found). It is far more traumatising a context to be giving a sample in, and completely avoidable additional trauma.*"

Families also noted that finding out about the recovery of human remains from media broadcasts, rather than being contacted to provide a reference DNA sample based on the possibility that it may be their loved one, was "*emotionally confusing, it added another layer of distress*". Learning from a secondhand source like the media, rather than the investigating police, was described by the father of a missing son as "*demoralising to read of such issues being reported in the press and in media without being advised beforehand*".

Forensic Procedures and Processes

Procedurally, families reflected on some ambiguity in the process described or demonstrated to them about their reference DNA sample:

> "*A clear outline of what the DNA (sample) could be used for was left deliberately ambiguous by (name of police jurisdiction).*" (Sibling of a missing person, since located deceased.)

For families who had a loved one missing outside of their home country, concerns regarding the safety of their sample were noted, as well as concerns that the police officer taking the sample might not be privy to the next steps of the forensic process.

"*I felt it was in incompetent hands*" explained the mother of a missing child, when (what the participant described as a) *junior* police officer was sent to collect the sample. Respondents noted that family members required certainty that samples would be collected both in a timely and competent manner, and with compassion.

Theme 3: Constructing Recommendations for Future Engagement Between Families and Practitioners Collecting Reference DNA Samples

In the final questions of the qualitative survey, respondents were asked to consider the ways in which reference DNA sample collection may be enhanced to support their journey of ambiguous loss. The underlying themes, deductively identified, suggested that the intersection between practical and emotional recognition needed to be underpinned by "*honesty and openness*" from policing jurisdictions:

> "*We wanted a testament from the officer about the importance (of what we were providing) and some gratitude of the contribution we were making to the missing persons investigation.*" (Sibling of a person missing for 5 years.)

Recommendations for enhanced privacy relating to the location of where the sample would be collected, the handling and storage of the sample, and the handling and storage of the resulting DNA profile were identified by the respondents. For example, *"I want them to be sensitive (to family's needs), I have an expectation of the need for an outline as to where the sample would go and who I would follow up with*" explained the mother of a missing person.

Some respondents noted that support was required during and after the provision of a sample. It was suggested by some respondents that police officers could attend homes without uniforms to soften the experience and provide information about referral services for families wishing to seek such services after providing a sample. As explained by the sibling of a missing person, missing for 5 years:

> "(what we need for collection is a...) *A neutral space. Police not wearing uniforms (perhaps just badges) ....and the process in detail including what will happen next – where it goes, how it will be stored/checked against, and how long it will take for the DNA sample to land where it needs to (weeks? months?). Then of course where they can go if they'd like more assistance before/after.*"

DISCUSSION

The respondents to this Australian survey of families of long-term missing people identified that the provision of a reference DNA sample was a potential trauma attached to their unresolved loss, through pre-occupation about human remains, or confirmation of the finality of their loss.

The survey analysis identified that much of the lived experience of having someone missing, involves real and imagined traumas about where the missing person may be, what has happened to them and when the loss will be resolved. Missing persons are people at risk, with this risk extending from the reasons why they are absent, to their welfare whilst their whereabouts are unknown (27). There are layers or elements of trauma that can be continually disempowering and confusing in terms of the realities of living with a traumatic loss that has no end, consistent with the evidence base exploring complicated grief, bereavement and ambiguous loss (14).

What was identified with the families who took part in this study, as distinctly different to the literature that focuses on victim identification following a mass disaster, is that the collection of a reference DNA sample can exacerbate grief ruminations (17) for the sample donor in situations where only one loss has occurred. These grief ruminations can offer insight into the impacts when only one loss occurs, compared to when there are multiple fatalities. These grief ruminations can include imagined aspects of the person's physical degradation, or even the likelihood that remains still exist. Without the connection to a group of others, such as in mass casualty events, who have experienced similar losses at the same time, families of individual missing experiences may be unaware that others are also living through similar experiences (9). The respondents to the survey noted that elements of the liminal space between hopefulness and hopelessness exist, even when practical aspects such as providing a reference DNA sample occur. For some families, the act of providing a sample may signify that they have *"given up hope"* for the safe return of the missing person, or that offering the sample suggests that their idea of a safe return may no longer be possible. Earlier work by author one noted that this concept of adding "*but.maybe*" to lived experience reflections of having someone missing meant that disappearances were characterized by a lack of extinguishment of hope for a possible return. This shifting to a potential reunion with physical remains is both traumatic for individuals to conceptualize and comforting in terms of finality (16).

Likewise, much of the previous literature on the lived experience of families of missing people refers to closure as not being possible for families of missing people given the inherent ambiguity of cases. Melnick and Roos (33) argue that closure has been a common feature of the social discourse surrounding response to loss where, however in the case of ambiguous loss, adjustment to life post-loss is not dependent on completing elements of grief reactions where closure may typically inhabit. When a disappearance occurs, each piece of information about the whereabouts of a person who is lost adds to iterative moments that lead to potential answers. However, in this study families spoke of the reference DNA sample providing a segue to potential closure, where the concept of closure was welcomed. The scientific certainty of their reference DNA sample *"matching"* to unidentified human remains offers finality in a way that no other information can provide; even in cases where a coronial investigation declares a person is deceased but no body has yet been located (34). Therefore, may alleviate the depression and prolonged grief disorder in family members of missing individuals, as seen in previous mass casualty events such as the 2004 tsunami, however it is unclear if these findings can be applied in single missing persons events due to the multifactorial reasons as to how and why people go missing, and what other impacts there may be on their mental health (35). Families may welcome the opportunity to provide a reference DNA sample to achieve this outcome, therefore challenging previous research (17) and requires further exploration in terms of developing strategies to assist families of the missing to live with their traumatic losses.

The additional finding of the study situated the role of *"others"*, and their significant impact on the wellbeing of those living with a loss. The role of police officers and their interpersonal skills in conveying empathy, compassion and clarity regarding the forensic procedure had a direct impact on the wellbeing of families during and after the provision of a sample. This is reflective of the literature on the certainty of those in positions of power offering warmth and connection to those experiencing trauma—particularly in the forensic field where sensitive engagement with families relating to human remains is noted (14). Enhanced training of police in both the scientific sampling of DNA and the ways in which this is verbally relayed to families may minimize vicarious trauma of both the police officer providing assistance and the family whose sample has been taken (23).

Finally, the literature reviewed in the earlier stages of this study identified that there are national and international guidelines relating to disaster victim identification—these map the connections between engagement with the scientific process and families' experiences of loss, in addition to awareness of their psychosocial needs (22). However, the desperate nature of single missing persons investigations where there is one person and one family are not covered by the same guidelines, despite the families having similar presentations to those involved in large-scale events like natural or man-made disasters. The International Committee of the Red Cross (ICRC) proposed a best practice guide for the DNA identification of missing and unidentified persons in situations of armed conflict or violence (23) that includes ethical and legal issues, but no context regarding emotional impacts. The resource did note the sensitive nature of a person's DNA and the concerns regarding the appropriate storage, handling and use of the DNA information, however the psychological or emotional impacts of the process of providing a sample, or the associated trauma of connecting the sample to a set of human remains, is not included.

The Australian Law Reform Commission's (2010) "*Essentially yours: The protection of human genetic information in Australia*" (36) report provides procedural, legal and privacy regulations regarding the collection and use of DNA samples that are voluntarily provided by kin. The only gray literature that links emotional support with the procedural awareness as to how DNA and forensic collection may impact families is in the AFP guide "*The SOS Guide: A guide for the families of missing people*" (26); with a section identifying emotional impacts. There are minimal resources that explore the process and traumatic impact, outside of scientific approaches or consent guidelines for families [see (37, 38)]. Ensuring that all practitioners collecting samples should complete ambiguous loss training as part of their core training requirements, to better support the aftercare needs of families of missing people, may assist in managing exposure to repetitive trauma.

Awareness of the connections between science, consent and emotional support needs may enhance the education requirements for professionals involved in single missing persons cases. Furthermore, the psycho-education needs of missing persons relatives should be treated through the lens of both the trauma response, and the procedural engagement. These concepts are worthy of future investigation.

LIMITATIONS

As with all research methods there are limitations due to the research design, when utilizing survey to elicit responses. The capacity to reach out to participants, during a time of significant covid impacts in Australia, provided scope for individuals to connect with the research in their own homes. Potentially enhancing the response rate. Additionally, the qualitative focus of the survey limits capacity to clarify or confirm responses with participants, however the depth of responses from respondents provided scope to understand the impact of a DNA sample and the narratives of their lived experiences in relation to an ambiguous loss. Considering the sample size, the research team were able to reach saturation of themes confirming research rigor and confidence in the research findings.

CONCLUSION

This study further extends the awareness that ambiguous loss and grief caused by the disappearance of a loved one can be considered by both the impact of the emotional and the practical requirements, and in this sense comparable to the effects of ambiguous loss. These presentations, in response to reference DNA sample collection, are linked to the experiences of ambiguous loss, where the lack of certainty about the finality of the loss and the waiting for confirmation of identity of human remains can provide cumulative impacts in an already traumatic situation. In this context, our respondents described the ways in which their personal reflections on the gravity of the provision of a sample, coupled with the professional behavior of police collecting the sample, offered an overt act of hope to enable them to consider the finality of their loss. The development and implementation of best practice guidelines for family reference sample collection considerate of both the technical and emotional aspects of undergoing a forensic procedure, outside those prepared for mass disasters will assist to minimize the vicarious trauma experienced by relatives already traumatized by the loss of their missing family member. Additionally, these guidelines should contribute to improving the families' awareness that there is a commonality of experience despite their lack of connection with other families in similar situations.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of New England Human Research Ethics Committee (HE21-136). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

SW is the lead researcher on the project. Both SW and JW designed the study, with SW overseeing the recruitment strategy and data collection period. Both researchers were involved in data analysis, with SW leading the writing of the manuscript and JW assisting with editing the manuscript and the scientific components of the literature review to ensure accuracy. Both authors approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.866269/full#supplementary-material

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Corrigendum: Dreading Yet Hoping: Traumatic Loss Impacted by Reference DNA Sample Collection for Families of Missing People

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Keywords: missing persons, DNA sample, traumatic loss, unresolved grief, ambiguous loss, unidentified human remains

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In the original article, the reference for (9) "Grewcock M. Slipping through the net? Some thoughts on the Cornelia Rau and Vivian Alvarez inquiry. *Curr Issues Crim Just*. (2005) 17:284–90. doi: 10.1080/10345329.2005.12036355" was included but not referenced. It has been removed from the reference list.

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In the original article, the reference for (36) "Isuru A, Hewage SN, Bandumithra P, Williams SS. Unconfirmed death as a predictor of psychological morbidity in family members of disappeared persons. *Psychol Med*. (2019) 49:2764–71. doi: 10.1017/S0033291718003793" was included but not referenced. It has been removed from the reference list.

In the original article, reference (3), "Ward J. The past, present and future state of missing persons investigations in Australia. *Aus J For Sci*. (2018) 50:708–22. doi: 10.1080/00450618.2018.1466535" was not cited in the article. The citation has now been inserted in Section **Introduction**, Paragraph one:

"The expectation is that some of these unknown remains will be linked to known missing persons, who in some cases have been absent for decades (3)."

In the original article, reference (10), "President's DNA Initiative. *Identifying Victims Using DNA: A Guide for Families*. Washington, DC: U.S. Department of Justice (2005). Available online at: https://www.ojp.gov/ncjrs/virtual-library/abstracts/identifying-victims-using-dna-guide-families-guia-para-las-familias" was not cited in the article. The citation has now been inserted in Section **Introduction**, paragraph two:

"Additionally, there are recently published international guidelines for police and forensic investigators regarding the use of DNA for humanitarian and mass disaster operations (7–9), and publicly available information brochures [e.g., (10)] and online resources (e.g., https://www.missingpersons.gov.au/support/national-dna-program-unidentified-and-missing-persons) for

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families to aid their understanding of the use of DNA for identifying human remains."

In the original article, reference (25), "Gin K, Tovar J, Bartelink EJ, Kendell A, Milligan C, Willey P, et al. The 2018 California wildfires: integration of rapid DNA to dramatically accelerate victim identification. *J For Sci.* (2020) 65:791–9. doi: 10.1111/1556-4029.14284" was not cited in the article. The citation has now been inserted in **Introduction**, Paragraph six:

"Unlike DNA identification of disaster victims, which are typically identified rapidly due to the high profile and public nature of the event, community expectations and provision of adequate resources, DNA identification may take an extended period of time for routine missing persons cases (25)."

The references have been renumbered as a result of other reference updates.

The authors apologize for this error and state that this does not change the scientific conclusions of the article in any way. The updated reference list appears below. The original article has been updated.

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ORIGINAL RESEARCH
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Beliefs About Causes and Cures of Prolonged Grief Disorder Among Arab and Sub-Saharan African Refugees

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Background: Many refugees have experienced the death of a loved one under traumatic circumstances. Accordingly, the prevalence of Prolonged Grief Disorder (PGD) among refugees is high. Culture-specific symptoms of PGD have been described previously, but beliefs about causes and cures of PGD among refugees remain unknown. We therefore aimed at identifying illness beliefs and treatment expectations regarding PGD among refugees.

Method: We focused on refugees from Arab countries ($n = 14$) and from Sub-Sahara Africa ($n = 9$) and applied qualitative and quantitative methods. In a semi-structured interview, participants first answered questions about assumed causes and potential cures for prototypical PGD symptoms according to ICD-11 that were presented in a vignette as representatives of their own culture. In the quantitative part, they completed the Cause Subscale of the Illness Perception Questionnaire (IPQ-R) that included additional culture-specific items. Interviews were analyzed with Qualitative Content Analysis.

Results: In both groups of refugees, PGD symptoms were predominantly attributed to a close relationship to the deceased, lack of social support, personal vulnerabilities, and circumstances of the death. Participants also named a number of flight-related causes (e.g., inability to perform or participate in rituals, feeling isolated in the host country). None of the participants attributed PGD symptoms to supernatural causes. Descriptive analyses of responses on the IPQ-R indicated that participants predominantly attributed PGD symptoms to psychological causes. Participants believed that PGD can be cured and predominantly mentioned social and religious support. Psychological help was only mentioned by a minority of participants. In both groups, participants emphasized that a therapist must be familiar with the patient's culture and rituals. Participants also mentioned stigma associated with seeking psychological help.

Conclusion: Results suggest specific beliefs of refugees regarding causes and cures of PGD as well as similarities with Western conceptualizations. A culture-sensitive approach to the treatment of PGD in refugees that can include knowledge of culture-specific rituals

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and incorporating religious beliefs as well as decreasing stigma and increasing mental health literacy seem important. The study is limited by its focus on only two groups of refugees and its small sample size.

Keywords: prolonged grief disorder (PGD), refugees, traumatic loss, help-seeking, beliefs, mental health, qualitative content analysis

INTRODUCTION

In the past 10 years, at least 100 million people worldwide have been displaced. With more than 2 million asylum applications, Germany recorded the highest number of applications in Europe during this period (1). Most refugees come from Syria, Afghanistan, Iraq, and countries of Sub-Sahara Africa such as Somalia or Eritrea (2). Many refugees report traumatic experiences and deaths of loved ones are among the most frequently reported events [e.g., (3)]. Accordingly, the prevalence of prolonged grief disorder (PGD) in refugee samples is high [e.g., (4, 5)]. PGD is a new diagnosis in ICD-11 and DSM-5-TR that is characterized by persistent and pervasive yearning for a deceased person and/or pre-occupation with this person that persist for an uncharacteristically long time (>6 months in ICD-11; ≥12 months in DSM-5-TR) (6, 7). Bryant et al. (8, 9) reported PGD prevalence rates of 15.8 and 15.1% in representative samples of bereaved refugees in Australia and Jordan, respectively. These numbers are about three times higher than the numbers from representative samples of bereaved Westerners after mostly non-violent loss [e.g., (10)]. However, the percentage of those refugees who receive adequate support for their mental-health problems is generally low (11, 12) and refugees are less likely to seek or be referred to mental health services (13–15). Given the prevalence of PGD, the high number of refugees in Western countries, and the general treatment gap, there seems to be a need to adapt grief-focused treatments to refugees' specific needs.

Although there is growing evidence of the cross-cultural validity of the PGD construct and its measures (16, 17), the expression of grief may differ within the respective cultural and religious frameworks (18, 19). A systematic review on the assessment of PGD in refugee and post-conflict samples (18) has shown that PGD can be identified with measures developed with Western samples. However, the few studies that used culturally adapted measures, revealed culture-specific symptoms of grief: somatic complaints, spiritual concerns, and dreams of or re-experiencing the deceased person were common expressions of impairing grief. These symptoms were highly prevalent and not captured by standard measures, thus pointing to the need of culture-sensitive assessment of PGD. A recent qualitative study with Syrian refugees identified emotional outbursts and weariness as additional symptoms (20). Furthermore, there is growing evidence that the conceptualization of mental disorders differs between cultural groups (21). Cultural barriers could therefore hamper the treatment of bereaved refugees in Western countries. To enhance the acceptability and effectiveness of psychological interventions for refugees, the cultural adaptation framework (21) suggests to systematically investigate the relevance of adapting treatment to (a) cultural concepts of distress, (b) treatment components, and (c) treatment delivery. It has also been suggested that treatments for refugees should promote established mechanisms of recovery in a culture-sensitive way and tailor treatments to patients' individual situations and life histories in order to reduce barriers (22). A recent uncontrolled study of grief-focused cognitive-behavioral therapy (CBT), that was integrated in a day-patient treatment program for refugees in the Netherlands, led to a large reduction in grief symptoms (23). Grief-focused CBT has been shown to be highly efficient in the treatment of PGD in patients from mostly Western countries (24) and the results by Djetlantik et al. (25) point toward the general effectiveness of common treatment elements for PGD (e.g., exposure to avoided stimuli or memories) in refugees. In addition, it has been argued that CBT programs for the treatment of refugees benefit from adaptations regarding content or structure [e.g., group setting, appropriate metaphors; (22, 26, 27)] that make programs sensitive for the target population's needs. To be able to make such culture-sensitive adaptations to grief-focused CBT, it would be an important starting point to learn more about refugees' illness beliefs and treatment expectations regarding PGD.

Several studies investigated lay beliefs about mental disorders among refugees in Western countries. A Somali sample distinguished three major types of mental problems: sadness or suffering ("murug"), craziness due to spirit possession ("gini"), and craziness due to severe trauma ("waali") (28). Grupp et al. (29) interviewed asylum seekers from Sub-Sahara Africa in focus groups about their beliefs regarding causes behind symptoms of post-traumatic stress disorder (PTSD) and identified traumatic life experiences, psychological causes, social causes, post-migration stressors, religious causes, and supernatural causes. In a larger survey part of the study, asylum seekers attributed symptoms more strongly to religious and supernatural causes than German participants without a migration background. Other studies also found that lay explanatory models of Sub-Saharan refugees emphasize supernatural influences or God's will (30, 31). Causes for depression were also seen in a person's social situation, especially being lonely and away from family, and the emotional reaction to difficult life (31).

Causal beliefs influence treatment-seeking and health care utilization (31). The perceived quality of health care can also be diminished by divergent expectations and frustrations can arise on both sides (32). Sub-Saharan refugees tend to seek help from religious treatments including prayer and religious authorities (28, 30, 33, 34) and traditional treatments such as herbal teas, natural remedies, or offerings (28, 34). Social support also plays a major role and Sub-Saharan refugees prefer to utilize the support from family and friends (28, 31, 33–35). Studies have shown that refugees from African countries are less likely to seek help from mental health professionals than people without a migration background (34) und under-utilize the available services (12, 33, 36) due to fear of stigmatization and lack of knowledge and accessibility (33). In an investigation with Syrian refugees in Germany, social support was also mentioned as one of the most important sources of support (37). While participants also mentioned seeking help from psychologists, there was no clear understanding of how mental health professionals work. Syrian refugees also reported more negative attitudes toward professional help than German residents despite higher levels of depressive symptoms and functional impairment that was mediated by lower tendency to disclose personal information and distress (38). Again, common barriers to utilizing help from mental health professionals were lack of information, stigma and language problems (37, 39).

Taken together, refugees from non-Western cultural groups tend to attribute mental health problems more to religious or spiritual causes or situational factors than to medical models behind Western treatment programs. Accordingly, they are likely to seek cures in religious and traditional treatments as well as social support. Mental health services are known, but fear of stigmatization and lack of knowledge are often barriers to their utilization. Although these findings provide valuable insights into how interventions can be tailored for refugees, they are based on investigations on mental health problems in general, or depression or PTSD and it is unknown if the same beliefs apply to PGD. Opinions about grief as a mental disorder have been explored in different cultures [e.g., (40, 41)], but perceived causes or treatment expectations have not been studied yet. The present study therefore aims to examine illness beliefs and treatment expectations of refugees regarding symptoms of PGD for the first time. We focused on refugees from Arab and Sub-Sahara African countries because they constitute important refugee groups in Germany. In Arab countries in Western Asia, Northern Africa, Western Africa, and Eastern Africa most people adhere to Islam that also shapes rituals and expectations surrounding grief. A 3-day funeral service attended by often large groups of extended family, friends, neighbors, and acquaintances is common during which emotions are expressed through crying or singing. This is followed by a 40-day mourning period for the family that ends by holding a funeral meal. During this time, support is offered to the family of the deceased. The term Sub-Sahara Africa is used for the group of countries that are located fully or partially south of the Sahara and that are heterogeneous regarding languages, ethnic groups, and religion. Christianity is the most common faith, followed by Islam, and traditional African religions that generally include animism and ancestor worship.[1]

We applied a mixed methods strategy by complementing a structured interview on beliefs about causes of PGD symptoms and treatment expectations with a questionnaire on the perceived causes of PGD symptoms. This combination enabled us to explore subjective meanings as well as theory-driven constructs.

METHODS

Procedure

A convenience sample was recruited between February and April 2020 *via* social media, word-of-mouth, and printed ads in places frequented by refugees. Target sample size was based on similar studies in this field [e.g., (28, 30)]. Inclusion criteria were being at least 18 years old and having come to Germany as a refugee from an Arab or a Sub-Saharan country. When potential participants contacted the study personnel, they received written and oral information on the study's aims and procedure. After providing informed consent, participation consisted of two parts: First, a semi-structured interview was conducted. At the beginning of the interview, participants were presented with a vignette that described a person with prototypical PGD symptoms. Interviews lasted about 60 min and at the end, participants received a link to an online survey where data about illness perception, loss history and own PGD symptoms, and sociodemographic information were collected. The survey took 20–30 min to complete and was available in German, English, and Arabic. Interviews were conducted with the help of an interpreter when necessary. Participants received a voucher for 10 Euros for their participation in the study. One person declined participation due to problems scheduling an appointment for the interview. The study was approved by the ethics committee of the Goethe University Frankfurt (reference numbers 2020-20 and 2019-57).

Materials and Measures

Vignette

A standardized vignette described a person with PGD symptoms according to ICD-11 and was presented at the beginning of the interview and the online survey. The vignette was adapted from a vignette of PGD symptoms presented in a study with a German sample without migration background (42). Assault was chosen as the cause of death because many refugees have experienced traumatic loss (23). The gender of the described person was matched to the participant's gender. The vignette was read aloud by the interviewer and shared via the computer screen and it was presented at the first page of the online survey. It read as follows:

> *A. is 35 years old and has been living in Germany for two years. Three years ago, her mother was assaulted in her home country and died. A. still cannot comprehend that her mother has died and has trouble fulfilling her everyday tasks. She is yearning for her mother and feels strong grief and intense emotional pain every day. She is thinking about her mother all the time. She ruminates about the circumstances of the death and asks herself if her mother was in pain and why it was her who died. She feels bitter and cannot accept the loss. She has strong feelings of guilt, because she was not with her mother and could not help her. She avoids things that remind her of her mother, such as telephone calls with her two siblings or news from her home town, because she fears that the pain might become too strong. Instead, she often looks at pictures of her mother because this makes her feel close to her. She feels she lost a part of herself and doesn't know who she is anymore without her mother and how her life should go on. Positive feelings are rare, instead she is angry and sad most of the time. A. has withdrawn from other people.*

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[1] Descriptions are based on explanations by study participants.

Interview

Interviews followed a semi-structured guideline (43) that was derived from the research questions and informed by the Cultural Formulation Interview in DSM-5 (44). In the beginning, the interviewer introduced herself, reviewed the goals of the study, and asked participants to answer questions as a representative of their home country or cultural group. She then asked questions about four main topics: (a) perception of pathological grief symptoms, (b) duration of grief, (c) beliefs about causes, (d) beliefs about cures (see **Supplementary Data Sheet 1**). If necessary, probes were given to further explain or elaborate on answers. For the present study, only responses regarding causes and cures were analyzed. The interviewer first asked participants to answer regarding the vignette and then to add anything they perceive important for grieving persons in general (e.g., "What do you think caused the described person's prolonged and impairing grief?;" "Do you think that prolonged grief disorder can be cured in general?"). Interviews were conducted by two female Master-level students in psychology who were trained in conducting the interviews by the first author. As the time of the data collection coincided with the COVID-19 pandemic and physical distancing regulations were in place, interviews were performed via a videoconferencing software. Participants were asked to select a private quiet place for the interview, interviewers were alone in a room when conducting the interviews. All interviews were recorded.

Illness Perceptions

Quantitative assessment of perceived causes of PGD symptoms was conducted with the Illness Perception Questionnaire–Revised [IPQ-R; (45)]. Only the subscale that captures causal assumptions of diseases was used. The original scale consists of 18 items (e.g., "personality," or "family problems"). For reasons of cultural sensitivity, three additional items ("God's will," "evil spirits," and "supernatural forces") were added based on previous research with non-Western samples (46, 47).

The original instruction was modified and participants were asked to indicate how likely they perceived each cause with regard to the person described in the vignette. Agreement was rated on a scale from 1 (strongly disagree) to 5 (strongly agree). The IPQ-R has demonstrated satisfying reliability and validity in previous studies (45, 47) and was also used to assess beliefs regarding symptoms presented in a vignette (29). IPQ-R versions were available in all three study languages (45, 48, 49).

PGD Symptoms and Interpersonal Loss History

Participant's own interpersonal loss history was assessed with items regarding how many members of the family and close friends had died (see **Supplementary Data Sheet 2**). If participants had experiences losses, the 18-item Traumatic Grief Inventory Self-Report Version [TGI-SR; (50)] was used to assess PGD symptom severity. Participants were asked to consider their most distressing loss and rate the extent to which they experienced grief symptoms during the last month on a 5-point scale from 1 (never) to 5 (always). A total PGD symptom severity score (range: 18–90) was calculated. The TGI-SR is a reliable and valid instrument for the measurement of PGD symptoms and has been used previously with refugee samples [e.g., (51)].

Sociodemographic Information

Sociodemographic characteristics and migration-related information (e.g., gender, age, country of birth, time since arrival in Germany; see **Supplementary Data Sheet 2**) were collected at the end of the survey.

Analysis

Qualitative Analysis

Reporting of the qualitative analysis and results is guided by the COREQ criteria [(52); **Supplementary Data Sheet 3**]. Interview recordings were transcribed verbatim and analyzed with the software MaxQDA using qualitative content analysis (53, 54). This systematic, rule-guided method of text analysis allows to analyze large quantities of text material and structure it according to a specific research question. The analysis follows a set of previously established steps, the most important being the development of a *category system*. This is a coding scheme that can be developed in an inductive (i.e., abstracting categories from the text) or deductive (i.e., developing categories based on theoretical principles) way. For each category, a category system includes a definition, coding rule, and anchor items (i.e., good examples of the category). With the help of the category system, categories are then assigned to previously defined coding units. To answer research questions pertaining to beliefs regarding causes and cures for PGD, one category system for each was developed inductively. Coding units were defined as paragraphs where participants answered questions regarding causes or cures or where they explicitly referred to causes or cures elsewhere during the interview.

The analysis was conducted in five steps. First, both authors read through all transcripts. Second, the first author (FLM) re-read the transcripts and started to develop categories that summarize causes and cures mentioned by the participants. After one third of the transcripts, the categories were checked for a comparable level of abstraction and category definitions were developed. Related categories were organized under superordinate categories. Coded paragraphs were checked for their fit with the categories. The first author then worked through the remaining number of transcripts assigning units to already existing categories and creating new categories when novel aspects emerged. After all transcripts were coded, she reviewed the category names and definitions. Third, the second author (HC) reviewed the category systems and coded units. Fourth, discrepancies were discussed and joint decisions made for the final code assignment. Frequencies for each category were calculated in the last step.

FLM is experienced in conducting qualitative research. Both FLM and HC have experience in working with refugees in research and clinical practice settings.

Quantitative Analyses

Responses on the IPQ-R and demographic characteristics were analyzed using SPSS 28. The IPQ-R response categories "agree" and "strongly agree" were combined into one broader agreement

TABLE 1 | Sociodemographic, migration-, and loss-related characteristics.

Characteristic	Total sample ($N = 23$)	Participants from Arab countries ($n = 14$)	Participants from Sub-Sahara Africa ($n = 9$)
Female, % (*n*)	56.5% (13)	50.0% (9)	44.0% (4)
Age in years, *M* (*SD*)	29.7 (14.6)	24.1 (10.3)	38.5 (16.5)
Country of birth, % (*n*)			
Syria	71.5% (10)	71.5% (10)	–
Yemen	14.3% (2)	14.3% (2)	–
Iraq	7.1% (1)	7.1% (1)	–
Egypt	7.1% (1)	7.1% (1)	–
Cameroon	11.1% (1)	–	11.1% (1)
Côte d'Ivoire	11.1% (1)	–	11.1% (1)
Congo	11.1% (1)	–	11.1% (1)
Eritrea	11.1% (1)	–	11.1% (1)
Ethiopia	11.1% (1)	–	11.1% (1)
Gambia	11.1% (1)	–	11.1% (1)
Ghana	11.1% (1)	–	11.1% (1)
Guinea	11.1% (1)	–	11.1% (1)
Somalia	11.1% (1)	–	11.1% (1)
Religion, % (*n*)			
Islam	65.2% (15)	92.9% (13)	22.2% (2)
Christianity	26.1% (6)	0.0% (0)	66.7% (6)
Not available	8.7% (2)	7.1% (1)	11.1% (1)
Time since arrival in Germany in years, *M* (*SD*)	8.3 (9.8)	5.5 (6.8)	12.6 (12.4)
Number of losses[a], *M* (*SD*)	1.8 (1.4)	1.5 (0.9)	2.4 (1.9)
Prolonged grief symptoms[b], *M* (*SD*)	34.3 (11.5)	32.4 (11.8)	38.5 (10.7)

–, not available. [a]Losses of significant persons were assessed with a loss questionnaire [see Comtesse and Rosner (4)]. [b]Symptoms of prolonged grief were assessed with the TGI-SR (50).

category. Absolute and relative frequencies of agreement with each of the 21 items were then computed for the total sample, the Arab sample and the Sub-Saharan sample. Due to the small number of participants in each of the two groups ($n = 14$ and $n = 9$, respectively), no tests for statistical significance were performed.

RESULTS

Sample

The sample comprised 23 participants. The Arab sample was slightly larger ($n = 14$) than the Sub-Saharan African sample ($n = 9$). Mean time since arrival in Germany was 5.5 years ($SD = 6.8$) in the Arab sample and 12.6 years ($SD = 12.4$) in the Sub-Saharan African sample. A detailed description of sociodemographic and migration-related characteristics is presented in **Table 1**.

Arab participants had experienced a mean number of 1.5 losses ($SD = 0.9$), Sub-Saharan African participants had experienced 2.4 losses ($SD = 1.9$) on average. None of the participants scored above the cut-off for PGD as measured with the TGI-SR. In response to the vignette, most participants described the PGD symptoms as familiar and many gave examples from people they knew. One participant (woman 2, Syria) spoke about her intense grief after the loss of her father.

Causes

Qualitative Results

The causes participants believed to be responsible for the symptoms, were grouped into four superordinate categories: (1) interpersonal causes, (2) intrapersonal causes, (3) circumstances of the death, and (4) separation from home and loved ones (**Table 2**).

Interpersonal Causes

Interpersonal causes were mentioned by 91.3% of participants and five sub-categories emerged.

Emotional Bond ($N = 15$). The category "emotional bond" was assigned when participants indicated that PGD symptoms develop because the bereaved person shared a close emotional bond with the deceased that was unique compared to their other relationships.

> *My cousin, when she lost her mom... you know her mom was her everything. And in the example, I don't know, if she [also] took her*

TABLE 2 | Causes of PGD symptoms.

Cause	Total sample (*N* = 23)		Participants from Arab countries (*n* = 14)		Participants from Sub-Sahara Africa (*n* = 9)	
	N	**%**	***N***	**%**	***N***	**%**
Separation from home and loved ones	7	30.4	4	28.6	3	33.3
Interpersonal						
Emotional bond	15	65.2	11	78.6	4	44.4
Kinship	11	47.8	8	57.1	3	33.3
Lack of social support	10	43.5	6	42.9	4	44.4
Material dependency	4	17.4	2	14.3	2	22.2
Aggravation by others	1	4.3	1	7.1	0	0.0
Intrapersonal						
Vulnerability	12	52.2	8	57.1	4	44.4
Guilt	7	30.4	6	42.9	1	11.1
Pre-existing mental health problems or traumatic experiences	3	13.0	2	14.3	1	11.1
Religious beliefs	1	4.3	1	7.1	0	0.0
Circumstances of the death						
Violent or unnatural death	8	34.8	7	50.0	1	11.1
Sudden death	7	30.4	6	42.9	1	11.1
Unable to perform rituals	6	26.1	2	14.3	4	44.4
Loved one died alone	1	4.3	1	7.1	0	0.0
Multiple losses	1	4.3	1	7.1	0	0.0

PGD, prolonged grief disorder.

> *mom as her everything. So when [my cousin] lost [her] mother, she can never find anyone like her mother again, do you get that? She can never never find somebody like her mom. (woman 10, Ghana)*[2]

Participants described strong bonds among family members, especially among parents, children, and spouses but also among friends.

> *Our families are very big, we have a lot of children, you know? But you only have one best friend, maybe two. And when one of them is not here anymore, you feel very lonely. (man 1, Syria)*
> *When I am only connected to one person and when this person cannot give me air anymore, then I'll die and when this person dies, I will die as well. Everything in my life is because of that person and not because of me. My luck is tied to him and when he is gone, I am also out of luck. (man 2, Syria)*

A strong emotional bond as a cause of PGD was more often mentioned by refugees from Arab countries.

Kinship (N = 11). The category "kinship" comprises statements where participants describe that PGD symptoms develop because the deceased was a next of kin. In contrast to "emotional bond," participants emphasized the kinship relation and the deceased's role in the family more than the quality of the relationship.

> *It's depending on the relationship. If the dead person is [someone] close and plays an important role in the family, there will be [. . .] long lasting grief in the family. If the dead person has no significance and plays a little role in the family, grief or mourning may not stay long. (man 9, Ethopia)*

This cause was also mentioned more often by refugees from Arab countries. Participants described strong family bonds, also in the important extended family.

> *Second, I would say the bond between family members in Arab families is so. . . there is this bond that they cannot leave each other. Or it is important that the whole family is there. (woman 4, Syria)*

Lack of Social Support (N = 10). Almost half of all participants perceived the cause of PGD symptoms in insufficient support by family, friends, or the community. They either described that support as unavailable to help the person manage the loss or that the available support is not sought by the bereaved.

> *Okay, so for example, someone is not married or has no close family, their grief is longer. That could be a cause. (man 5, Syria)*
> *When you lose someone close and you don't have any other friends or so who you are as close with. Yes, I believe people with many friends and relatives grieve less. (woman 7, Yemen)*

Some participants specifically described greater loneliness and less support in Germany in comparison to their home country.

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[2] Quotes from interviews conducted in German were translated into English by the first author.

> *. . . because at home you are not alone. You have family, you have brothers, sisters, cousins, the village community or friends who support you. But here, this loneliness, this being alone. (man 10, Ivory Coast)*

Material Dependency (N = 4). The category "material dependency" was assigned when participants indicated that PGD symptoms develop because the relationship to the deceased was characterized by a dependency on their resources. They described, for example, a financial dependency and how losing the person leads to a crisis and difficulties to uphold one's life. For widows, this also includes a role reversal when they suddenly need to provide for their family.

> *Because the man has a special role in our families. Not when it comes to raising children, that is a women's responsibility. But everything else, such as going to work, I mean making MONEY and EVERYTHING is done by the man. And now [when he dies] it is a burden on the women, because she must take over his role. (woman 6, Yemen)*

More statements regarding the importance of material dependency were made in the Sub-Saharan sample. Participants also described the value of a successful family member, irrespective of gender.

> *So when the person is a breadwinner in the family, the person is supportive to everyone in the family. Let's say my mom is the only person that takes care of the family, providing us with food and shelter. And if we lost her, we would grieve for so many years to keep her in mind, because we can never and ever find someone like her again. (woman 10, Ghana)*

Aggravation by Others (N = 1). One person from Iraq assumed that unhelpful social interactions intensify the grief reaction and cause avoidance symptoms described in the vignette.

> *Or as I said, sometimes the atmosphere in a family also plays a role. When the mother of that man in the example, maybe in Iraq or somewhere, is also grieving and when he calls, she talks about it AGAIN and cries, this can also be a cause. (man 7, Iraq)*

Intrapersonal Causes

Causes for PGD symptoms that lie within the person were mentioned by 69.6% of all participants.

Vulnerability (N = 12). The category "vulnerability" was assigned when participants expressed that PGD symptoms are caused by a predisposition in the person's personality or an acquired predisposition during their upbringing. Participants often described being too emotional or not having enough strength to cope with loss.

> *There are strong people, but there are also weak people and everyone copes depending on their condition. That's why it is quicker for some and prolonged for others. There are people who by nature cannot deal with pain. Maybe that is a general cause. (woman 12, Cameroon)*

Guilt (N = 7). Seven participants explained how they see pervasive feelings of guilt as a cause for PGD symptoms.

> *She is probably feeling guilty, more or less because she thinks that she did not help and questions why this happened to her mother. (woman 5, Egypt)*

Guilt was most often mentioned in context of being separated from the family due to the flight. Being unable to care for them before they died was perceived as a strong source of guilt. This explanation was more common among Arab participants.

> *I believe that she feels guilty because she was far away from her mother for a long time. For me, that would be a reason when my mother died now to be sad all the time because I left HER and left her alone. That would kill me. I would think about her forever and think "I should have come back or I should have just stayed." (woman 6, Yemen)*

Pre-existing Mental Health Problems or Traumatic Experiences (N = 3). Three participants indicated that a mental health condition that existed before the loss or previous traumatic experiences are causes of PGD symptoms.

> *But when people were sad before or always depressed and then, on top, someone dies, then [the grief] will be prolonged. (woman 6, Yemen)*
> *That requires so many aspects of trauma that someone withdraws like that. . . otherwise I could not explain it. Eritrea is a traumatized country because of the war and even people who can flee have experienced bad things. Women [have experienced] a lot of abuse, rape, scenes of murder and so on. (woman 9, Eritrea)*

Religious Beliefs (N = 1). One participant from Syria referred to ruminating about God's reasons behind the death as a cause of PGD. This person emphasized how religion is interwoven with nearly all aspects of life.

> *In Syria, everything is connected to religion. No matter what happens, God planned it for us; no matter what happens, God will save us or punish us. [. . .] And if you are religious, [grief] is prolonged, because you think "Why did this happen? Why not me? What did I do to God? Did I pray enough?" And so on and so on and then it takes a long time and then you become depressed and you are sad. It is so prolonged because you have so many questions and don't get answers. (woman 4, Syria)*

Circumstances of the Death

Causes that are related to the circumstances of the death were mentioned by 65.2% of the sample and were grouped into five subordinate categories.

Violent or Unnatural Death (N = 8). Eight participants perceived violent or unnatural circumstances of the death as the cause for PGD symptoms. They either referred to the assault described in the vignette or described war-related circumstances of loss in general. The impact of a violent or unnatural death was often compared to loss after a longer disease or a sudden condition like a heart attack.

> *The circumstances of the death. If your mother dies after a long illness and in her bed in peace it is different than when she is assaulted and stabbed to death with a knife. That is something you cannot understand and think "My mother was a good person, why did someone something like that to her?" In my opinion, that is how someone could get prolonged grief disorder [...]. (woman 12, Cameroon)*

Participants from Arab countries, especially Syrian participants, mentioned traumatic loss more often. They described how people die under atrocious circumstances (i.e., torture) and that seeing or knowing how much the loved one has suffered intensifies grief.

> *So imagine a mother who for years sacrifices her life and her resources for her child. And then this child dies, yes this happens often that a bomb drops, and a splinter kills somebody. And this does not feel real anymore, how can this happen that THIS child was hit by a bomb. And unfortunately, it is also common that young people and elders are imprisoned and they are tortured and then two or three months later, [their body] will be passed on to their parents and you see... Well, they say "Was hit by a car" but you know this is not the truth, you can tell from the body how much the person suffered. And it is EVEN HARDER when the body is not returned, but just disappears. You can really grieve when you know someone is dead. (man 3, Syria)*

Sudden Death (N = 7). Seven participants expressed that they see a sudden, unexpected death as the cause of PGD. Statements in this category emphasized the suddenness of the news of the death more than the circumstances. Again, more statements were made by participants from Arab countries.

> *It is a possible cause—I mean in general and probably in this example—that you do not expect that the father... It is so sudden, a phone call and they say "Your father is dead." And he thought that this is 20 or 30 years away. And maybe this shock does something. (man 7, Iraq)*

Unable to Perform Rituals (N = 6)

The category "unable to perform rituals" comprises statements regarding the importance of rituals. Participants described religious or spiritual rituals as well as sharing grief in the community in a ritualized way. Being unable to perform or participate in rituals, such as the funeral, due to the flight or living in a country where rituals are not possible, was perceived as the cause of PGD symptoms.

> *It is even more painful when you can't be there for the funeral. There are rituals related to the funeral that need to be done. For example, as a Muslim you would wash the body and dig the grave and walk all the way from your home or the mosque to the graveyard. Some people drive but many do walk. It's these rituals [the man in the vignette] is missing. (man 1, Syria)*

Rituals were more often mentioned by participants from Sub-Sahara Africa who described rituals surrounding the funeral and the wake and how painful it is not being able to participate.

> *He would have liked to be there that day [of the funeral]. I told you that we give a message to the deceased before we close the coffin. People from the family, even people from the village community come to the coffin, everyone brings their message: "If you meet my father, tell him I have problems here. Tell him, he needs to see my problems and help me." And they will give their message to the deceased. And when you are far away and not part of the ceremony, that hurts. I would have liked to be there to tell my mother and father "That is my problem, my situation" so that it can get easier in Germany. And that causes additional grief, right? [...] This tribe, this people don't only see the deceased as a deceased, it is not only a goodbye but also a transformation into a different state. The person hears and SEES what happens to the bereaved. They can help solve our problems and improve our situation and I would like to be there to give my problems to the person so that they can help solve the problems when they get to next level. And I cannot do that when I am 10.000 km away and that is additional grief, a potentiation of my grief. (man 10, Ivory Coast)*

Loved One Died Alone (N = 1). One participant from Syria believed that PGD symptoms developed because the person was not with the loved one when they died.

> *She could not be there [when her mother died]. I believe it can be more difficult compared to when you are with the person who is dying. Yes, I believe that is most difficult. (woman 2, Syria)*

Multiple Losses (N = 1). Another participant from Syria suggested that PGD symptoms develop when more than one loss occurs within a short period of time.

> *In some cases, like with my aunt, she was very happy before [her husband and her mother died] and behaved normally and that it was so extreme all of a sudden is just because she lost TWO people at once. (woman 6, Yemen)*

Separation From Home and Loved Ones (N = 7)

According to seven participants, PGD symptoms are caused by being far away from the home country due to the flight or migration.

> *And regarding causes, first, I would say it is the long distance between the home country and Germany. (woman 2, Syria)*

Statements also include the separation from the family and participants explained that grief can become prolonged when someone had not seen the deceased for a long time before they died.

> *When you have not seen each other in a long time. For example, someone who came to Germany to go to university and has not seen their parents in three or four years. And then the parents die. The person will not [get over it] ... That could be a cause, a general cause. That is connected to grief, not having seen the parents in a long time. (woman 12, Cameroon)*

IPQ

In the questionnaire survey (see **Table 3**), participants endorsed "one's emotional state" (95.7%, $n = 22$), "stress or worry" (82.6%, $n = 19$), and "one's mental attitude" (82.6%, $n = 19$) as predominant causes behind PGD symptoms. Participants from Arab countries also attributed symptoms to "one's personality" (92.9%, $n = 13$) and "family problems or worries" (92.9%, $n = 13$). Agreement with religious and supernatural causes was markedly lower: 39.1% ($n = 9$) of the sample agreed with "God's will" (Arab sample: 42.9%, Sub-Saharan African sample: 33.3%), 17.4% ($n = 4$) with "evil spirits" (Arab sample: 7.1%, Sub-Saharan African sample: 33.3%), and 13% ($n = 3$) with "supernatural forces" (Arab sample: 14.3%, Sub-Saharan African sample: 11.1%).

Cures

Participants suggested different cures or treatments for the person described in the vignette and for people suffering from PGD in general. Cures were grouped into four superordinate categories: (1) interpersonal and professional help, (2) individual behaviors, (3) religion and spirituality, and (4) other cures (**Table 4**). Obstacles to treatment and healing were also discussed.

Interpersonal and Professional Help

The majority of participants (87.0%) regarded interpersonal or professional help as the most effective way to overcome PGD symptoms. Four subordinate categories emerged.

Social Support (N = 18)

Support from other people was perceived as most important in order to help someone with PGD symptoms. Participants explained that others can help by simply listening or providing an opportunity to share grief, but also by providing distraction and support in daily life.

> *Just talk, social connection especially to people who have been friends before and family, that can help. Everything that has to do with social connection. In the Mediterranean culture, I believe people are more sociable or socially oriented. For example, I have never heard that somebody who was bereaved said "I don't want anyone here," or something like that, I have NEVER heard that. It COULD happen, but that is an isolated case. (man 5, Syria)*

Support by family and friends was mentioned most often. Participants explained how valuable help from friends with similar experiences can be and emphasized the importance of a strong bond, trust, and understanding.

> *The only help that can be given to the person is when somebody is there to talk to her. Somebody just sitting down, talk to her, advise her and help her and if she needs any help, the person is ready to support her. [. . .] That is the only way to let the person forget about the dead mother. Because if no one is there to talk to her or to bring the person down or to support the person like the mother did before she died, she will be disturbed emotionally [. . .]. (woman 10, Ghana)*

Participants also described the importance of offering support to others in the family or community. They explained how supporting the bereaved is also part of rituals and their culture.

> *Sometimes I invite people when we have an event in our community. Something cultural, something educational, or sometimes we just meet to EAT together or something like that. And I look for people who are psychologically distressed by their grief so that they can mingle and don't have to stay so sad. (man 7, Iraq)*

The social withdrawal described in the vignette was perceived as concerning and strange by a few participants. One participant explained how this behavior stood in sharp contrast to what he is familiar with:

> *I think it's weird that he avoided contact with his siblings because normally with us, in Syria, you try and get in touch with more people who were close to the bereaved. So for example, there are three, four, or five siblings and all of a sudden, the mother dies. Then these five siblings try to be even closer to each other so that they don't feel that the mother is suddenly gone. That was strange for me that the person did not want to be in touch with people who were close to the father. I believe this is how you could treat him. You could treat him after the death with bringing him closer to people who were also close with the deceased. (man 1, Syria)*

Mental Health Professionals (N = 12)

About half of all participants mentioned that seeking help from therapists, psychologists, or psychiatrists is important and were positive that these mental health professionals can help someone who suffers from PGD symptoms.

> *Okay. The professional people they can help, because they are trained to do that. So they can help, they can talk to them, they can advise them and they know how it's affecting them emotionally and help them to forget about that. So I think the professionals, they can really, really help. Yeah. (woman 10, Ghana)*
> *Yes, [my aunt] also realized she is different and she needed help and then she expressed that and went to see a doctor, a psychologist. (woman 6, Yemen)*

Some Sub-Saharan participants agreed that therapists can be helpful when probed by the interviewer, but generally professional help was regarded only as an option when social support or religion did not help.

> *When somebody does not have a circle of friends, someone who says "You are like me. I also lost my father but look at me, I am still living" or "Do what I do," when someone does not have this opportunity then psychologists or therapists or whoever are needed to support them. (man 10, Ivory Coast)*
> *Then you can only look for help in therapy. [. . .] If the person has prolonged grief despite having attended the funeral, he cannot do it on his own or others don't understand him. This condition is difficult. He needs someone to talk to, a therapy, a talking therapy. He needs someone who listens [. . .]. He really needs help.[. . .] (woman 12, Cameroon)*

Participants also emphasized the differences between mental health services in their home country and in Germany. Some explained that they would seek help from therapists in Western host countries, but not in their home country.

TABLE 3 | Causes of PGD symptoms assessed with the Revised Illness Perception Questionnaire (IPQ-R).

	Total sample ($N = 23$)		Participants from Arab countries ($n = 14$)		Participants from Sub-Sahara Africa ($n = 9$)	
IPQ-R Cause	***N***	**%**	***N***	**%**	***N***	**%**
Stress or worry	19	82.6	12	85.7	7	77.8
Hereditary	7	30.4	4	28.6	3	33.3
Germs or virus	1	4.3	0	0.0	1	11.1
Diet or eating habits	8	34.8	5	35.7	3	33.3
God's will	9	39.1	6	42.9	3	33.3
Chance or bad luck	4	17.4	2	14.3	2	22.2
Poor medical care	8	34.8	5	35.7	3	33.3
Environmental pollution	2	8.7	1	7.1	1	11.1
One's own behavior	17	73.9	10	71.4	7	77.8
One's mental attitude	19	82.6	12	85.7	7	77.8
Family problems or worries	18	78.3	13	92.9	5	55.6
Evil spirits	4	17.4	1	7.1	3	33.3
Overwork	14	60.9	11	78.6	3	33.3
One's emotional state	22	95.7	14	100	8	88.9
Aging	12	52.2	9	64.3	3	33.3
Alcohol	8	34.8	5	35.7	3	33.3
Smoking	6	26.1	3	21.4	3	33.3
Supernatural forces	3	13.0	2	14.3	1	11.1
Accident or injury	11	47.8	7	50.0	4	44.4
One's personality	18	78.3	13	92.9	5	55.6
Altered immunity	7	30.4	6	42.9	1	11.1

PGD, prolonged grief disorder; IPQ-R, Revised Illness Perception Questionnaire.

> *In Western cultures [mental health services] are advisable (laughs). I would recommend or at least say "Okay, talk to someone." (woman 9, Eritrea)*

Find Someone to Take the Place of the Deceased ($N = 3$)

Participants from Arab countries mentioned that finding someone who takes the place of the deceased might cure PGD symptoms. They described that this can either be someone in the family who takes over the role of the deceased (e.g., mother takes over the role of the father) or someone else who becomes the new best friend. One participant also rejected this idea.

> *Or [finding] a substitute for the deceased, but maybe that's out of the question. Some people try that, it happens in our culture, that people try to comfort you and say "Yes, you lost your brother but you have three other brothers." For me, that was always a strange method because one person cannot replace another. But sometimes people try that. (woman 3, Syria)*

Support Groups ($N = 2$)

Two participants from Arab countries suggested seeking help from support groups. These groups can either be official or unofficial with the defining aspect that people who had similar experiences support each other. Because of the shared experiences as the main characteristic, these groups go beyond social support described above.

> *Maybe by connecting to other people who are in the same situation, for example people who also lost someone due to an assault, and by talking about it together and everyone shares how they cope and everyone tries it until they have arrived in their daily life again. (woman 5, Egypt)*

One person explained that support groups often remain unofficial because of stigma but that this kind of structured support exists nonetheless.

> *Support groups, but they don't exist under the name of support groups. People like to do that VERY much, very much for many many topics. It's really like that, people WANT to help but they don't say that they are a support group, because no one has the COURAGE to say "We are a support group for people with this specific disorder" because no one wants to disclose having this disorder. But as soon as someone says in a meeting or among friends "I have this problem," people come and say "Yes, I also experienced that and my neighbors and my aunt they did this and that and that helped." (woman 3, Syria)*

Individual Behaviors

When discussing cures, many participants (69.6%) described different individual behaviors that were grouped into seven subordinate categories.

TABLE 4 | Cures of PGD symptoms.

	Total sample (*N* = 23)		Participants from Arab countries (*n* = 14)		Participants from Sub-Sahara Africa (*n* = 9)	
Cure	***N***	**%**	***N***	**%**	***N***	**%**
Religion/spirituality						
Belief in God/spiritual beliefs	10	43.5	8	57.1	2	22.2
Belief in life after death	4	17.4	3	21.4	1	11.1
Accept the loss as God's will	3	13.0	3	21.4	0	0.0
Interpersonal or professional help						
Social support	18	78.3	12	85.7	6	66.7
Mental health professionals	12	52.2	4	28.6	8	88.9
Find someone to take the place of the deceased	3	13.0	3	21.4	0	0.0
Priests/elders	2	8.7	0	0.0	2	22.2
Support groups	2	8.7	2	14.3	0	0.0
Individual behaviors						
Focus on the present and pursue goals	7	30.4	6	42.9	1	11.1
Recognize and express painful emotions	6	26.1	5	35.7	1	11.1
Remember the deceased	5	21.7	4	28.6	1	11.1
Overcome guilt/think differently	3	13.0	2	14.3	1	11.1
Live like the deceased would have wanted you to do	3	13.0	3	21.4	0	0.0
Complete rituals	2	8.7	1	7.1	1	11.1
Avoid reminders	1	4.3	1	7.1	0	0.0
Other cures						
Time heals	2	8.7	1	7.1	1	11.1
Understand the reasons for one's reactions	1	4.3	0	0.0	1	11.1

PGD, prolonged grief disorder.

Focus on the Present and Pursue Goals (N = 7)

The category "focus on the present and pursue goals" comprises statements regarding how the bereaved should focus on what they can do in the present or future rather than dwell on the loss. Participants gave examples of fulfilling activities of daily life but also mentioned pursuing long-term goals. They regarded this way of living as a possibility to take the person's mind off the loss that stands in contrast to withdrawal. More statements in this category came from participants from Arab countries.

> *If someone has a hobby, they can do more of that. For example, some people write or paint. (woman 1, Syria)*
> *Commit to a specific goal in your life. He will continue his life, it will not stop, he will live his life but with a goal. Without a goal, it's nothing. (woman 2, Syria)*

Recognize and Express Painful Emotions (N = 6)

Six participants explained that they see a cure for PGD symptoms in becoming aware of grief and other negative emotions and finding a way to express them. Participants also described cultural differences regarding the expression of emotions. A woman from Eritrea explained that it is common in her home country to share and express emotions and she perceived this as healing. A participant from Syria explained different expectations regarding the expression of emotions depending on the gender of the bereaved. While it is expected from women to show their emotions, the opposite is true for men which may hinder their coping with loss. More statements were made by participants from Arab countries.

> *We have a proverb, it says "Crying or tears clean your soul." And that's why we think it's good to be able to cry or something like that. (man 7, Iraq)*
> *Just talking? Talking is the key to everything, for me personally, the key to everything. Open communication, where you express your emotions and cry. In the example, it's a woman, right? When we refer to men, I would say in the Arab culture, it's not okay that men cry. I would say it should be normalized that men cry and talk about their emotions because it is normal, it's because we are humans and not men and women. (woman 4, Syria)*

Remember the Deceased (N = 5)

Actively bringing up memories of the deceased, talking about them, and engaging in activities that remind of them was emphasized by five participants as being helpful in overcoming PGD symptoms. More statements were made by participants from Arab countries.

> *For Syria, I would say when you lost someone you bring up memories more rather than keeping them at bay. People like it VERY much to talk about things they did with the deceased, what connected them, how strong their bond was, which emotions they still have related to the person, and sometimes that helps. If you*

> *don't do for too long, I would say it is helpful. If you occupy yourself INTENSELY with the topic for some time, then [grief] lessens and then you can find your way back into daily life. (woman 3, Syria)*

Overcome Guilt/Think Differently (N = 3)

Finding a new way of thinking about the loss was perceived as helpful by three participants. With reference to the vignette, they especially mentioned overcoming guilt.

> *The example was about how the young woman blames herself, she had feelings of guilt. If she only forgave herself that she could not be there, that would be an immense help. To admit to herself, "Okay, I could not be there, I forgive myself." (man 1, Syria)*

Live Like the Deceased Would Have Wanted You to Do (N = 3)

Three participants from Arab countries described living one's life in a way that would make the deceased happy as helpful. They gave examples such as choosing a career path that the deceased would have approved of or not being weighed down by grief too long but investing in one's future.

> *When someone was very important to you then I believe it is very effective when you say "This person would not have wanted me to throw my life away for nothing but to continue living and invest in my life." (man 3, Syria)*

Complete Rituals (N = 2)

One participant from each group perceived it as helpful when the bereaved completes important rituals associated with death, such as visiting the grave, or grieving with the community. This might also mean that someone must return to their home country.

> *One cure would be to send the person back to his home country so that he can visit the grave. That would be painful, but that would give him peace, [...] calm his thoughts. It will change something, will make something go away, you feel that, that difference. That's what it's like when you live in different countries. (woman 12, Cameroon)*

Avoid Reminders (N = 1)

One participant from the Arab group discussed that reminders that are too painful should be avoided in order to overcome PGD symptoms. She was drawing on experiences with a family member.

> *She wanted to avoid the contact that always brought up painful memories or that reminded her of the person who died and that helped her. And that's why we needed to pay attention when my aunt was there [...] that we do not talk SO much about my grandmother like "Grandma was like that and she did this." No, we did not do this because it's not worth it. She died and it brings only grief and my aunt would be very sad. (woman 6, Yemen)*

Religion and Spirituality

Seeking help in religion or spirituality was perceived as helpful by 53.3% of all participants. Four subcategories emerged.

Belief in God/Spiritual Beliefs (N = 10)

A belief in God or spiritual powers was perceived to be of great importance. Participants explained how a strong belief, praying, or observing rituals may be the best help when someone is suffering from PGD symptoms.

> *I can imagine that religion or a belief in God would make it easier for me. I used to work a lot with refugees and we had a program with a lot of psychologists and people told their stories how they came to Germany and how they lost people during their flight. There were extreme cases like one woman who said "I have lost my CHILD, I have SEEN how he died" and she can NEVER forget. Only the belief in God helped her. (woman 6, Yemen)*

The belief in God was more often mentioned by participants from Arab countries who were all Muslim.

> *In my opinion, when you want to help people who are suffering from that, when you are working with Muslims, you should take a religious approach. (man 4, Syria)*

Some explained that the loss can be seen as a test from God that one needs to pass and that religious beliefs can motivate the bereaved to overcome grief.

> *And the religion says that people who cope better and who have more patience in such cases will be rewarded by God. And this motivates you to keep it together and not break down when someone dies now. (woman 3, Syria)*

Belief in Life After Death (N = 4)

The category "belief in life after death" comprises statements regarding the belief that it will be possible to see the deceased again in the afterlife and that the deceased is living a better life now. Participants perceived these beliefs can be specifically helpful when someone is suffering from PGD symptoms.

> *And then you also believe that the person who died, when it was wrongful that they were killed, then you believe this person is some kind of martyr and has a special place with God. And that's why you should not grieve so much because the person went to a better place. This also exists in Christianity, that you go to heaven and that you are in a better place. (man 3, Syria)*
>
> *How you deal with the dead also depends on the upbringing and the culture you were born into. We Africans, we live with the dead. For us, the dead are not gone. They are not here anymore, we cannot touch them anymore, but they are present. That's why our original religion is this worship of ancestors. We pray to our ancestors, to those who have already died, who are with GOD and who can help US. And if you know that, that heals grief. You know, the deceased goes to the ancestors, to the grandparents and those who have died will built a community. That CURES, yes. (man 10, Ivory Coast)*

Accept the Loss as God's Will (N = 3)

Three participants from Arab countries emphasized that accepting the death as something that was wanted by God can help to cure PGD symptoms. These statements were related to the belief in life after death, but more tied to acceptance of the loss in the here and now than to the afterlife.

> *And sometimes the sermon in the mosque. It helps when they say you have to be patient and you have to accept because everything came from God and then you have to accept what it is. They say that in the mosque. (man 7, Iraq)*

Priests and Elders (N = 2)

Two participants from Sub-Sahara Africa mentioned that seeking support from religious authorities as the most important treatment.

> *In Africa, there are no jobs for psychologists. Psychologists in Africa are the priests, the pastors. We are also lawyers [laughs], this and that, and psychologists. When the person does not belong to an institutionalized religion, when he is an animist, that means traditional, there are two options. [...] A psychologist cannot help a traditional person. [...] If he is caught in this feeling, only older people who have grown up in this tradition can talk to him and show him other ways of tradition. (man 11, Congo)*
>
> *In the case of Ethiopia, priests and elders, right? They play very, very important roles. Are addressing such problems. Many social problems, many problems related to stress that are caused by losing someone beloved or other relatives. Such kind of problems are addressed by such persons and such institutions. Such institutions play very, very important roles as social therapy in Ethiopia. (man 9, Ethopia)*

Other Cures

Two other cures that could not be grouped into the categories described above were described by three participants (13%).

Time Heals (N = 2)

One participant from each group expected that PGD symptoms become less intense with time without additional help.

> And of course you need time to cope. I am not saying time heals all wounds but maybe you learn how to deal with it. (woman 9, Eritrea)

Understand the Reasons for One's Reactions (N = 1)

One participant from Sub-Sahara Africa mentioned that it is important to understand the reason behind the person's intense grief and build the treatment on that.

> *Everything happens for a reason [...]. So when you know the reason, you can think about a solution. Then I think this solution can be the treatment for this person's situation. (woman 11, Somalia)*

Obstacles

When participants talked about potential cures, about half of them (52.2%) also mentioned obstacles they perceive in the treatment of someone with PGD.

Mental Health Stigma (N = 4)

Four participants talked openly about mental health stigma. They described that seeking support from mental health professionals or disclosing prolonged grief as a mental health problem can lead to being labeled as crazy or being regarded as an outsider. The anticipation of these reactions can prevent people from seeking help.

> *It is not normal to see a psychologist because then the whole family will be judged as strange like "Oh, they are treated for psychological symptoms, they are crazy." You don't see a psychologist and if you do then you don't talk about it. I know how people suffer who talk about it [...]. They don't only say "I'm ILL," they will also be regarded differently from the COMMUNITY and they need to accept that people will give them funny looks and talk behind their back and say "She is ill, she is crazy, she needs to take medication, that is not normal." (woman 6, Yemen)*
>
> *But in our society in general we have a problem with psychiatrists, for example, or with seeing a psychologist. It's like "Why should I, I am not a sick person," it is not accepted, it really is a taboo. I cannot image that I go to someone who has prolonged grief disorder in Syria and tell them "You need to see a psychologist." Then they say "I am only grieving and how can you recommend something like that or imply I am mentally ill?" That doesn't work and one should not try it. (woman 3, Syria)*

Bereaved Person Has to Want Help (N = 4)

Participants from Arab countries emphasized that PGD symptoms can be cured but only if the person is willing to accept help.

> *When he would accept help, then yes, [symptoms could be cured]. If not, the best therapy cannot help him. (man 2, Syria)*

Old Age (N = 3)

Three participants from Arab countries perceived it as more difficult to help someone with PGD in older age. They described that behaviors, thoughts, and relationships of young people are easier to change and older people might have less resources.

> *I would say for people who are older, over 50 or 60, it is not as easy as for younger people. They won't be as open and they won't accept everything because they will think "No. What we think is correct because we are grown up and know better than young people." I can understand that [laughs]. It is difficult because I cannot imagine talking to an older woman saying "NO, you just have to accept that. And you have to forget what has happened and you have to make your children's lives easier." She would not say "Okay." So, I think that is not easy, [...] especially when we talk about Arab families. (woman 4, Syria)*

Therapist Cannot Help (N = 3)

Three participants from Sub-Sahara Africa disclosed doubts regarding Western therapists. They specifically emphasized that in order to help someone, a therapist must understand the patient's culture and important traditions related to loss.

> *How can I say it? I am a bit uncertain regarding these psychologists. I have not been in therapy in my life so far, but I know something from my friends who have been in therapy because they could not deal with situations on their own or because they had disorders. I know that. But how far can a psychologist go? There is a person who comes to them saying "I have just lost my father and I cannot manage." For me, the psychologist needs to be familiar with the person's culture, the culture they grew up in, with the traditions*

> *regarding grief, and with their life and reality in Germany. And then the person can help, but when they only know from books, when they read something or learned something at university, I think it will be the wrong way. (man 10, Ivory Coast)*

One participant also described that therapists are only consulted by "severe cases" and that grief should be dealt with within the family.

> *But in our society, there are no services for [someone with prolonged grief], there are no psychologists. Well, there are psychologists, but they are for the severe cases, not for someone who grieves. [...] The psychologist will be the family, an uncle, an aunt or someone from the family who will try. They are no psychologist, they have no method, but they will try [...] to elicit positive feelings. (woman 12, Cameroon)*

Close Relationship to the Deceased Person ($N = 2$)

Two participants expressed doubts about healing PGD when the relationship with the deceased was very close.

> *As I said, I find this difficult... If the best friend died or is gone, I believe it is the most difficult thing to help someone. (man 1, Syria)*

DISCUSSION

The study combined semi-structured interviews with a questionnaire-based survey in order to complement Arab and Sub-Saharan African refugees' subjective beliefs about causes and cures of PGD with established constructs. In the qualitative part of the study, causes for PGD symptoms were either seen in interpersonal aspects, intrapersonal aspects, or factors associated with circumstances of the death or separation from loved ones. Most participants attributed PGD to a close familial or emotional relationship with the deceased, lack of social support, pre-existing vulnerability, or guilt related to the death. Flight-related aspects that include traumatic experiences and circumstances of the loss as well as the inability to care for loved ones and participate in rituals surrounding the death were perceived as particularly important. Participants in both groups did not express supernatural beliefs. Likewise, in the quantitative part of the study, participants attributed symptoms to psychological factors and rates of agreement for supernatural causes were much lower. All participants believed that PGD symptoms can be cured and named interpersonal and professional help, individual behaviors, and religion and spirituality as potential cures. In line with the belief about social causes, they were most inclined to expect help from family, friends, and social support in general. The majority of participants did not initially mention psychological treatments or even voiced concerns regarding stigmatization or being understood by Western therapists.

Although the study was not designed to elicit differences between the two cultural groups, some interesting tendencies emerged. Especially statements from Syrian participants made clear how sudden deaths under traumatic circumstances (e.g., bombings, torture) impact grief reactions and these statements were clearly shaped by the ongoing war in Syria. Consistent with the literature (55), Arab participants also put more emphasis on religion and the belief in God. The large difference regarding agreement with mental health services as a cure for PGD—88.9% of Sub-Saharan participants made statements regarding mental health professionals but only 28.6% of Arab participants—can be explained by the way the interviews were conducted. The person who interviewed the Sub-Saharan group asked about opinions regarding mental health professionals when participants did not make a statement on their own while no such follow-up questions were asked in the Arab group. Some Sub-Saharan participants agreed that therapists can be helpful, but generally professional help was regarded only as an option when social support or religion did not help.

Lay explanatory models in our study partly overlap with established risk factors and models for PGD. Previous research has shown that a perceived lack of social support is a risk factor and that PGD is more likely after the loss of a close relationship or a death under unnatural circumstances (25, 56). For refugees, the role of migration- or adaptation-related difficulties and lack of rituals in PGD has also been documented (19, 57). Dysfunctional cognitions, including guilt, also play a major role in the development and maintenance of PGD symptoms [e.g., (58)]. Although opinions about grief disorders and their expression have been investigated in different cultures [e.g., (20, 40, 41)], there are no studies on perceived causes of PGD. However, there are several studies on beliefs about the causes of mental health problems in general or PTSD or depression specifically in different cultural groups. Beliefs expressed in the study are also consistent with findings regarding lay beliefs about causes of PTSD among refugees (29), especially regarding the role of traumatic life experiences and social causes. However, in contrast to previous research that showed a preference for supernatural explanations especially in cultural groups from Africa [e.g., (30, 31), participants in the present study did not offer any supernatural explanations in the interviews and only few agreed in the questionnaire survey. While Grupp et al. (29) also found that supernatural explanations should not be overstated, this was even more pronounced in the present study. There are several explanations. First, participants in this study had lived in Germany for a mean duration of 8 years and it is possible that they had somewhat adopted Western perspectives or experienced that supernatural explanations are not shared by the majority society. Second, symptoms of PGD vary from normative grief reactions in intensity and duration, but they are generally more familiar than symptoms of depression or PTSD because normative grief is a universal experience. It therefore seems possible that people are less inclined to search for supernatural explanations.

Treatment expectations were overall directed at ameliorating the factors that were believed to have caused PGD symptoms. Hence, healing was expected from re-engaging with the family and the community. Increasing social support is indeed one element in some evidence-based treatments for PGD [e.g., (59)] and a focus on grief-related daily problems has also been found to be helpful (60). Participants also put much emphasis on religious or spiritual authorities and practices which is in line with previous findings regarding the role of religion in help-seeking of refugee groups [e.g., (28, 30, 33, 34)]. While participants described their belief as a source of comfort, it is important to note that reliance on religious authorities can also be a gatekeeper to seeking health care (31, 33, 34).

It is noteworthy that social support and religion were perceived as the first-line help in this study. Although some participants mentioned mental health professionals, it was clear that they had reservations and perceived barriers to their utilizations. We did not ask participants about their knowledge of the health care system and it is possible they were not familiar with available services and their methods as some statements as well as past research has indicated (34, 37). Mental health services are often not well-known by refugees because less mental health care is available in their countries of origin (38). Some participants also struggled with understanding what we mean by PGD and the interviewers needed to take time to disentangle beliefs about normative and disturbed grief. This may have been due to PGD being a new diagnosis that is not well-known yet, but other studies have also found that a lack of mental health literacy in general is a barrier to help seeking in refugee groups (61–63).

Participants also named mental health stigma as an obstacle to seeking help for PGD symptoms and mentioned fears of being ostracized from the community. Previous research has repeatedly shown that stigma is among the main barriers to seeking help for mental health problems (37, 64). It is also of importance that expectations from mental health professionals were low because some participants did not believe that a Western therapist could understand them. This concern was also voiced by Sub-Saharan asylum seekers regarding the treatment of PTSD (34) and problems with trust were previously reported by mental health providers (63). Together with treatment expectations, these perceived obstacles have implications for the adaptations of interventions for refugees suffering from PGD.

Implications for Cultural Adaptation

Our findings support the need for a culturally sensitive approach to PGD treatment when working with refugees. Three aspects seem important in order to reach refugees with PGD with psychological interventions: (1) overcome barriers to help-seeking, (2) establish a shared explanatory model, and (3) adapt treatment components and delivery.

Psychological interventions for PGD are successful (24), but therapy was not among the first choices for participants in our study. In order to prevent a large treatment gap for PGD, barriers to help-seeking need to be overcome. First, it seems important to reduce stigma through low-threshold interventions or campaigns, preferably supported by members of the respective cultural groups. A short intervention specifically directed at reducing stigma has been shown to be successful (65). There is also a need for education about PGD as a mental health problem and available services. This can be done with general intervention programs aimed at newly arrived refugees [e.g., (66)] or interventions that increase engagement with therapy (67). Working with religious authorities may be a way to prevent them from becoming gate keepers. Therapists also need to take concerns regarding trust and being understood seriously. As the numbers of patients from diverse cultural groups can be expected to rise in the future, training for therapists needs to focus on delivering treatment in a culture-sensitive way and therapists from the majority society need to make an effort to understand their patients' experiences, traditions, and expectations.

Evidence-based treatments are based on their specific models for the development and maintenance of PGD. In order to engage patients in therapy, models should be adapted to patients' beliefs insofar that patients share the rationale behind the treatment (21). When treating refugees with PGD, individual models can include and educate about established factors of PGD development (e.g., avoidance behavior) and combine them with a patient's individual important aspects. This means that, for example, for patients from collectivistic societies, the role of support by family and community can be included in a model. Beliefs expressed by participants in the present study also underline the importance of addressing flight and post-migration-related aspects. Therapists should, for example, ask about the circumstances of the loss and their meaning. If not offered by the patients, therapists should also inquire about traditions and rituals surrounding a death and if they could be completed.

As adapted interventions are more effective than non-adapted versions of the same intervention (68), treatment components and their delivery also need to be adapted (21). As some treatment components of evidence-based intervention programs matched our participants' expectations, these programs seem well-suited for the treatment of refugees. Combining them with culture-specific rituals and religious dimensions and tailoring delivery and materials to patients' need can result in a culturally sensitive treatment.

Rituals can be integrated into therapy (69). If they cannot be completed in real life, it may also be possible to use mental imagery that can have a powerful impact resembling real-life experiences (70). If religious practices or authorities are important for a patient, they can be consulted or also incorporated into therapy. Furthermore, findings regarding the importance of social support point toward group settings as an option for treatment delivery. The needs of patients from predominately collectivistic cultures could be met by enhancing mutual support and at the same time it would be possible enroll more patients in a shorter period of time, thus significantly reducing waiting times for therapy.

Limitations and Implications for Future Research

Despite some valuable insights, the study has number of limitations. First, the small sample size does not allow generalization and especially the Sub-Saharan African sample and non-Syrian Arab sample were very heterogeneous regarding countries of origin. Potential differences between the cultural groups included in the study and beyond need to be examined in future studies. Second, while the vignette allowed for a specific presentation of PGD symptoms, it is also possible that open interviews would have generated slightly different responses. As we did not include a comparison group without a migration background, we cannot infer that refugees' beliefs differ from those held by German residents. Future studies that conduct direct comparisons between larger refugee and non-refugee groups are therefore needed. Third, data collection took part at during the first weeks of the COVID-19 pandemic in Germany when regulations for physical distancing were in place. Interviews were therefore conducted online which made working with interpreters more difficult. Interviews were mostly conducted in German or English which constitutes a selection bias. A slight language barrier still remained in some interviews. This was more often the case for Sub-Saharan African participants and could explain why more ideas were offered by Arab participants. Conducting interviews in the participants' native language could therefore lead to deeper insights in future studies. COVID-19-related difficulties also hampered recruitment and we interviewed all participants who volunteered during the specific time period and did not continue until data saturation was reached. Last, interviews were conducted by white females without a migration background. Although participants expressed that they find the study valuable and were willing to explain rituals and cultural perceptions in detail, their responses may have been shaped by social desirability.

Conclusion

Our findings suggest that mental health professionals should explore and understand the relationship with the deceased and circumstances of the loss in conflict regions as well as important rituals when working with refugees with PGD. At the same time, cultural differences should not be overstated, because beliefs about causes showed similarities with Western conceptualizations. The expressed treatment expectations underline the importance of reducing stigma surrounding mental health care and increasing knowledge. With some adaptations, available PGD treatments have the potential to also meet refugees' needs. Future studies on different cultural groups and culture-sensitive treatments for PGD are needed.

DATA AVAILABILITY STATEMENT

The dataset generated for this study can be found in the **Supplementary Material**. The qualitative data presented in this article are not readily available to protect the privacy of the participants. Reasonable requests to access the data should be directed to the first author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee of the Goethe University Frankfurt, Fachbereich 05. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

FL-M and HC developed the study design, supervised the data collection, conducted the analyses, and wrote the manuscript. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.852714/full#supplementary-material

Supplementary Data Sheet 1 | Interview guideline.

Supplementary Data Sheet 2 | Questionnaires.

Supplementary Data Sheet 3 | COREQ checklist.

Supplementary Data Sheet 4 | Survey data.

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My Grief App for Prolonged Grief in Bereaved Parents: A Pilot Study

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The death of a child is a devastating experience for most parents. Consequently, bereaved parents are at risk to develop physical and mental health problems, including prolonged grief disorder. Nevertheless, there is a lack of evaluated psychosocial interventions for bereaved parents. The primary aim of this study was to examine the feasibility of the My Grief app for bereaved parents. The secondary aim was to evaluate the potential reduction of symptoms of prolonged grief, depression and post-traumatic stress, and cognitive-behavioral processes proposed to prolong grief reactions. The study was a mixed-method open trial design, using pre- and post-intervention surveys and post-intervention interviews. Thirteen parents had access to the app for 4 weeks, eight parents participated in interviews and 10 parents answered the follow-up survey. The study provided evidence for the app's feasibility and acceptability, with participants reporting satisfaction with the app and stating that they would recommend it to parents in similar situations. According to the participants, the app was easy to use, the content gave a feeling of not being alone or weird in how one grieves, and the app gave a valuable overview of information, knowledge and further support. In addition, all parents expressed that an app like My Grief is needed and would be particularly useful to access early in the grieving process. Significant reductions of prolonged grief symptoms ($d_{within} = 0.86$) and grief-related rumination ($d_{within} = 0.72$), loss avoidance ($d_{within} = 0.95$) and negative cognitions ($d_{within} = 1.36$) from pre- to post-assessment were found. In conclusion, the app appears acceptable and feasible to use and will be evaluated in a larger randomized controlled trial (Trial registration number: NCT04552717, https://clinicaltrials.gov/ct2/show/NCT04552717).

Keywords: bereavement, intervention, parents, pediatrics, prolonged grief, smartphone application

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INTRODUCTION

The death of a child is one of the most devastating events that a parent can experience. Most bereaved people come to terms with the loss without requiring professional help or support. Common experiences in the initial month following the loss of a loved one are sadness, yearning, anxiety, and feelings of emptiness. Generally, these feelings decrease over time as the bereaved person adjusts to the loss (1). However, several studies show that a substantial subset of bereaved parents develops various physical and psychological health problems that persist many years after the loss (2, 3). Bereaved parents are also at a heightened risk for developing persistent, severe and disabling grief, commonly termed prolonged grief or complicated grief (4, 5). Recently, diagnostic handbooks have recognized prolonged grief disorder (PGD) as a formal diagnosis. It is characterized by persistent and pervasive yearning for the deceased, persistent and pervasive cognitive preoccupation with the deceased, as well as symptoms of intense emotional pain, such as difficulty accepting the loss, a feeling that one has lost a part of one's self, and difficulty in engaging in social activities (6). One study found that 16% of parents bereaved of a child due to cancer showed responses signaling probable PGD (7).

Despite the potentially severe consequences of losing a child, there is a lack of evaluated psychosocial interventions for bereaved parents (8, 9). However, cognitive-behavioral therapy (CBT) is generally shown to be effective in treating prolonged grief symptoms both face-to-face (10–13) or internet-based formats in bereaved adults (14–16). CBT treatment for PGD includes creating a coherent, meaningful narrative of oneself regarding the loss, challenging negative beliefs about the self, the world and the future, and gradually confronting avoided reminders of the loss such as places, memories, or objects. It also includes setting new life goals and stimulating engagement in meaningful activities (17). Some studies have focused on using complementary therapeutic techniques (e.g., mindfulness and relaxation exercises) to ameliorate prolonged grief symptoms (18–20).

Self-help applications in smartphones (apps) have several advantages over face-to-face and web-based intervention, such as their availability, accessibility, the immediate support they can provide, as well as their anonymity, low costs, and the possibility of tailoring it to the user (21). Thus, mobile apps have a great potential to be used as self-help interventions for stress-related mental health problems. A literature review of the effectiveness of mobile apps for mental health problems has shown that using mobile apps can decrease different mental health problems, such as depression, anxiety, substance abuse, sleeping disorder and posttraumatic stress disorder (PTSD) (22). For example, one app focused on reducing mental health problems following major negative life events is the *PTSD Coach,* a self-management app focused on improving knowledge of PTSD symptoms and providing support for trauma-related distress (23). A recent randomized controlled trial (RCT) on the Swedish PTSD Coach showed a reduction in posttraumatic stress and depression symptoms compared to a waitlist control group (24). Several studies on the PTSD Coach further show that the participants generally experience no or few adverse negative effects of using the app and support the acceptability and feasibility of using the app (24–27).

Based on existing knowledge, we believe that an app targeting bereaved parents who lost a child, using elements of CBT, could potentially be effective in improving mental health in those parents. To our knowledge, no apps for bereaved individuals have yet been empirically examined. This pilot study aimed to elucidate the feasibility of the app My Grief in bereaved parents. A secondary aim was to provide a preliminary evaluation of the potential effect of using the app for 1 month on prolonged grief, depressive and posttraumatic stress symptoms, and cognitive-behavioral processes proposed to perpetuate grief reactions (i.e., grief rumination, anxious and depressive avoidance, and negative grief cognitions).

MATERIALS AND METHODS

Design

This study is part of a larger study aimed to evaluate My Grief for parents who lost a child (28). The present study evaluates the parent's use of the app for 4 weeks. Four weeks of app access was considered sufficient to evaluate the feasibility of the intervention based on a previous pilot-study of PTSD Coach (25). The study has an open trial mixed-method design, using pre- and post-intervention surveys and post-intervention interviews.

Intervention—The Self-Management App My Grief

This intervention entailed receiving access to a self-management app called My Grief (in Swedish called *Min Sorg*), available for smartphone users (iOS and Android), in Swedish. The content in the app is based on CBT principles, and a cognitive-behavioral conceptualization of prolonged grief, which includes three tasks: (1) Facing the loss and the pain that goes with it, (2) keeping confidence in yourself, others, life and future, and (3) engaging in activities that may promote adjustment to the loss (10, 29). The app is also based on an online PGD-treatment manual (30, 31). The structure of the app is based on the PTSD Coach and parts of the self-guided exercises are from the Swedish version of the PTSD Coach. My Grief includes four sections (see **Figure 1**), which are: (1) *Learn*—psychoeducation about grief, (2) *Self-monitoring of grief intensity*—a rating scale to assess the daily intensity of the grief, (3) *Exercises*—self-guided exercises, both recorded audio exercises (e.g., mindfulness exercises) as well as writing exercises (e.g., exposure to memories of the loss) and (4) *Get support*—contact details to different support functions and help-lines, and psychoeducation regarding expanding one's social network. For further information about the content, structure, and exercises of the app, see the study protocol (28).

Settings and Participants

Parents were recruited from the Swedish Childhood Cancer foundation via their social media sites during April 2021. Inclusion criteria for participation were being a parent of a child who died at least 1 year ago, having mild to severe symptom levels of prolonged grief [a cut-off of >16 on the PG-13 was chosen to include parents with elevated PGD symptoms, as individuals with mild to moderate symptoms could benefit from the intervention (24)], understanding and speaking Swedish,

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Abbreviations: App, A smartphone application; CBT, Cognitive behavioral therapy; PGD, Prolonged grief disorder; PG13, Prolonged Grief Disorder-13; PTSD, Post-traumatic stress disorder; RCT, Randomized controlled trial.

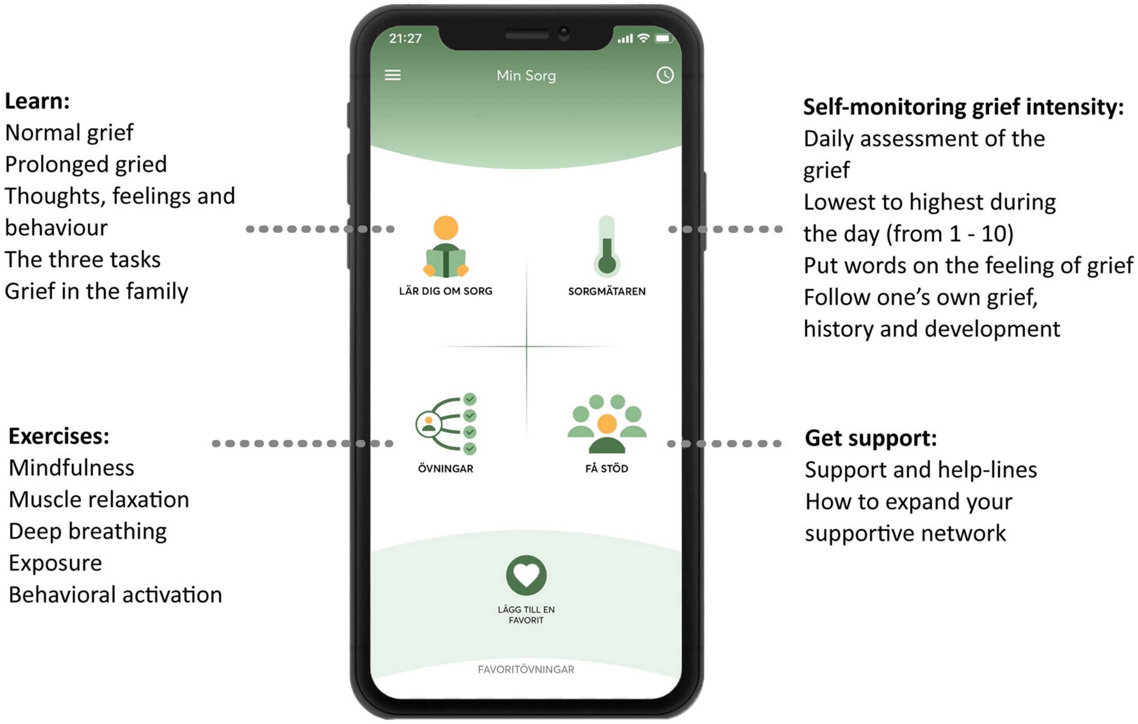

FIGURE 1 | Structure of the *My Grief* app.

and having access to a smartphone. Exclusion criteria were self-reported current suicidal thoughts or psychosis, assessed with single items in the screening questionnaire. The parents signed up for the study via a website, www.minsorg.com, which automatically directed the parents to a screening questionnaire and, if they were eligible, to the informed consent form and the pre-intervention survey, all at an online platform hosted by Uppsala University.

A total of 27 parents filled in the screening survey, to assess if they were eligible to participate in the study, whereof eight parents were excluded due to having suicidal thoughts [for full inclusion and exclusion criteria: (28)]. Of the 19 eligible participants, five did not give consent to participate. Of the 14 who consented to participate, 13 parents completed the pre-intervention survey and thereafter got access to the My Grief app for 4 weeks. One week after enrolment, a researcher from the research group called the parents by phone, to check that everything was working out properly with the app, to answer any questions about the app or the study, and to set up a time for a telephone interview. After 4 weeks, 10 parents filled in the post-intervention survey and eight parents were interviewed by telephone; these 10 and eight parents were included in the quantitative and qualitative analyses, respectively (**Figure 2** shows a flowchart).

Ethical Approval

The study has received ethical approval from the Swedish Ethical Review Authority (project no. 2020-01704).

Data Collection

Interviews

Semi-structured telephone interviews were conducted by one of the researchers (RE), 4 weeks after the parents had received access to My Grief. The aim of the interviews was to elucidate how the parents had used the app, which parts in the app were used the most and least, and to receive suggestions for improvements (see interview guide, **Supplementary Material**). Eight parents participated in the interviews. Five remaining parents did not want to participate as they indicated they did not use the app that much ($n = 1$) or they could not be reached ($n = 4$). The interviews lasted between 14 and 45 min, were audio-recorded, and transcribed verbatim.

Survey

The survey consisted of questionnaires assessing prolonged grief, depression and posttraumatic stress symptoms, cognitive-behavioral variables (i.e., grief rumination, anxious and depressive avoidance, negative grief cognitions) as well as feasibility and user experiences of the app.

Prolonged grief was measured by Prolonged Grief Disorder-13 (PG-13). It consists of 13 items including 11 items assessing cognitive, behavioral and emotional symptoms during the past month, rated on a 5-point scale (not at all—several times a day/overwhelmingly). It also contains two items on duration and impairment (yes/no). PG-13 is scored by adding scores from the 11 items assessing symptoms. The total score ranges from 11 to 55, with higher scores indicating more severe prolonged grief

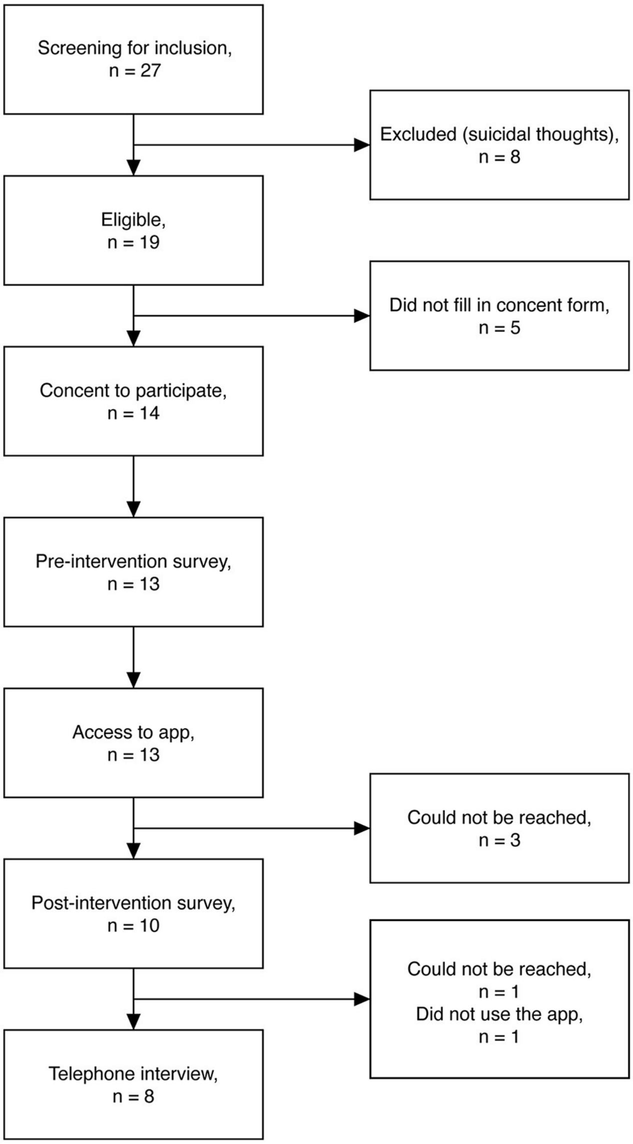

FIGURE 2 | Flowchart over recruitment and pre-post assessments.

symptoms [based on PGD criteria per (32)]. The instrument has been validated in a Swedish sample with bereaved parents and was demonstrated to have satisfactory psychometric properties and a preliminary cutoff score of ≥ 35 indicating probable PGD (7).

Depression symptoms were measured with the Patient Health Questionnaire (PHQ-9), which consists of nine items describing symptoms of depression. Participants rate to what extent they experience these symptoms during the last 2 weeks on a 4-point scale (not at all—nearly every day, 0–3). The total score ranges from 0 to 27. A higher score indicates greater symptom severity and a cutoff score of ≥ 10 may indicate probable depression (33, 34).

Posttraumatic stress disorder symptoms were measured by the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5). It consists of 20 items describing symptoms of posttraumatic stress. Participants rate on a 5-point scale (not at all—extremely, 0–4) to what extent they experience symptoms. The total score ranges from 0 to 80, and a higher score indicates more symptoms of posttraumatic stress (35) and a total sum of ≥31–33 points may indicate probable PTSD (36). The Swedish version has shown satisfactory psychometric properties (37).

Grief-specific rumination was measured by the Utrecht Grief Rumination Scale (UGRS). The instrument consists of 15 items measuring different aspects of grief rumination. The participants' rate on a 5-point scale (never-very often, 1–5) how often they experienced certain thoughts over the last month. Total scores range from 15 to 75 and generate an overall grief rumination score (38). The instrument is validated in a Swedish sample with bereaved parents and indicates satisfactory psychometric properties (39).

Grief-specific avoidance was measured with the Depressive and Anxious Avoidance in Prolonged Grief Questionnaire (DAAPGQ). The questionnaire consists of nine items; five items measure depressive avoidance of activities and four items measures anxious avoidance of cues reminding of the loss. Participants rate on an 8-point scale (not at all true for me—completely true for me, 0–7) to what extent they engage in these avoidance strategies (40). The total score ranges from 0 to 72. The DAAPGQ was translated by two of the authors (RE and JS) following the EORTC guidelines (41).

Negative grief-cognitions were measured with the short version of Grief Cognitions Questionnaire (GCQ-18). It consists of 18 items, with statements regarding negative grief cognitions. Participants rate on a 6-point scale to what extent they agree with the statement (disagree strongly—agree strongly, 0–5). The total score ranges from 0 to 90 and a higher score indicates a stronger endorsement of negative cognitions (42). The GCQ-18 was translated by two of the authors (RE and JS) following the EORTC guidelines (41).

Eleven items from the PTSD Coach app survey (26) were revised to fit the current study, 10 items assessing the perceived helpfulness of the app, rated on a 5-point scale ranging from 0 "not at all" to 4 "extremely" and one item about the overall satisfaction of the app, rated on a 4-point scale ranging from 0 "not at all satisfied" to 3 "very satisfied." User-experience of the app were also measured, including if the participant experienced technical problems and if the app met the participant's expectations, and if they would recommend the app to parents in a similar situation. Negative effects were assessed through the question: "Did you experience any stressful or negative consequences of using the app?" Participants who answered yes were asked to provide details in a free-text response.

Data Analysis

A thematic analysis was used to analyze the interviews (43). The transcripts were read several times by the first and last author to get a sense of the whole and find patterns of meaning. Thereafter, the first author coded the interviews, and then a collaborative reflective process took part between the first and last author with a focus on the aims of the study and the research questions. When the dataset was coded and all codes were compared and discussed between the first and last author, the first author grouped the data into preliminary themes based on similarities and differences in the data. Next, the analysis process was conducted jointly. The analysis resulted in two themes "*experiences of the different sections and their content*" and "*the overall use and experience of the app*" with ten codes for identified themes.

Descriptive statistics were used to summarize the socio-demographic variables and to summarize the quantitative findings. The Wilcoxon paired samples test (2-tailed) was used to test for differences in prolonged grief, depression, posttraumatic stress symptoms, and rumination, negative grief cognitions and anxious and depressive avoidance, between the two assessments. Within-group effect sizes, Cohen's *d*, corrected for the correlation between paired samples (44), were calculated as a metric of the standardized mean difference between the pre- and the post-assessments. SPSS Version 28 was used for the quantitative data analysis.

RESULTS

Participant Characteristics

Of the 10 participants included in the analyses, nine were women and one was male. Demographic variables of the parents and their deceased children are presented in **Table 1**. At the pre-assessment, the average levels of prolonged grief were relatively high (**Table 2**). Five of 10 participants scored above the cutoff (≥35) for probable PGD. One participant scored above the cutoff for probable depression and two participants scored above the cutoff for probable PTSD.

TABLE 1 | Demographic characteristics for parents completing pre-assessment (total sample) and parents completing the post-assessment (completers).

	Total sample (*N* = 13)	Completers (*N* = 10)
Age (years)		
Mean (SD)	47.38 (5.79)	46.80 (6.39)
Gender		
Female/Male	11/2	9/1
Place of residence		
Large city/City/Town or smaller town/Rural area	5/2/4/2	4/2/3/1
Country of birth		
Sweden/Other	12/1	9/1
Highest education level		
University/High school/Primary school	9/3/1	8/2/0
Current employment status		
Working/Pregnancy leave	12/1	9/1
Marital status		
Married or co-living/Single	12/1	9/1
Number of children		
(Including those who died) Mean (SD)	2.92 (1.03)	2.90 (1.19)
Lost another child		
No/Yes	13/0	10/0
Years from time of diagnosis		
Mean (SD)	6.30 (3.61)	6.00 (2.66)
Years since death[a]		
Mean (SD)	4.81 (1.96)	4.81 (1.96)
Diagnosis		
Leukemia/Brain Tumor/Other	5/5/3	5/3/2

[a] *Data from 8 children, due to that the question were asked during the interviews and not in the baseline survey.*

Results From Interviews

Experiences of the Different Sections and Their Content

Section 1—Learn

The section regarding psychoeducation was appreciated by almost all participants. The sections about complicated grief and siblings' grief were regarded as especially good according to three of the parents. Five of the eight interviewed parents expressed gratitude to have all information gathered at one place, as one mother described it: *to have it all in one place, so good, that makes it so good. There is nowhere else, I tell you, I haven't found, I had to search through myself and participated in courses and read every single book that I came across* (mother no. 11). However, two parents, who had lost their children 5 years ago, expressed that this part of the app was not so useful to them, as they already knew a lot about grief and that this information would have been more helpful earlier in the grieving process.

Section 2—Self-Monitoring Grief-Intensity

Regarding the self-monitoring grief-intensity section, the parents' experiences were divided, either the parent really appreciated it or they did not. The four parents who appreciated the grief-intensity self-monitoring said that it was easy to use and that it clarified a pattern over their grief. It helped clarify for the parents that they were not always in a sad or bad mood, that some days actually could be just fine: *but there* [in the self-monitoring section] *I got the insight that yes, but today it has not been so hard and it was kind of nice sometimes to get a confirmation on it too* (Mother, no. 18). Two parents expressed that they were not in "a phase of grief" right now and that the self-monitoring was hard to use because of that. Three parents also expressed that it was difficult to use this section because they then had to think about the loss, it elicited memories. It was especially hard to fill in during the evening, just before going to sleep: *I went like into grief again at bedtime and started to think about the loss and I felt it was just so hard when I would go bed and sleep* (Mother, no. 17). Three of the eight parents reported that they used the self-monitoring section every day, while five parents used it a lot at the beginning of the 4-week study period, but less toward the end. Two parents, who had lost their children 3 and 5 years ago, suggested that this element may have been more useful at the beginning of their grieving process.

Section 3—Exercises

Overall, the parents appreciated the section which included different types of self-guided exercises. They were short and therefore easy to integrate into everyday life. The parents appreciated that the section included so many different exercises and the range of the offered exercises: *I think it covers a wide spectrum of exercises that are… easily accessible… and are short which you can get into everyday life… so no I think the exercises themselves are good… I think this particular section is… for me*

TABLE 2 | Mean scores, Standard deviations (SD) and Effect sizes (Cohen's d) of within-group differences for the outcome measures.

	Total sample	Completers		
	Pre-assessment ($N = 13$)	Pre-assessment ($N = 10$)	Post-assessment ($N = 10$)	Cohen's d_{within}
	M (SD)	M (SD)	M (SD)	
Prolonged grief (Prolonged Grief Disorder-13)	34.6 (7.6)	34.6 (7.9) Range (min-max): 24–49	30.7 (6.0) Range (min-max): 24–41	0.86
Depression (Patient Health Questionniare-9)	8.2 (4.6)	8.1 (4.7)	7.1 (4.7)	0.44
Posttraumatic stress (Posttraumatic Stress Disorder Checklist-5)	23.5 (13.8)	21.4 (13.6)	19.4 (14.6)	0.26
Grief rumination (Utrecht Grief Rumination Scale)	48.5 (14.7)	47.0 (12.5)	40.8 (14.3)	0.72
Anxious avoidance (Depressive and Anxious Avoidance in Prolonged Grief Questionnaire)	17.0 (4.8)	17.1 (4.7)	14.7 (6.5)	0.95
Depressive avoidance (Depressive and Anxious Avoidance in Prolonged Grief Questionnaire)	20.6 (7.5)	17.9 (6.1)	16.5 (8.0)	0.37
Negative grief cognitions (Grief Cognition Questionnaire 18)	31.0 (17.5)	29.3 (16.4)	22.9 (16.9)	1.36

the big benefit, which I think, both now and many years ago, would have used the most and… which had given… most results (mother, no. 17). The parents reported that they used the audio exercises several times a week. Exercises were appreciated by almost everyone. The audio exercises consisted of mindfulness training (e.g., seated practice, walking practice, awareness of the senses) and relaxation (e.g., deep breathing and body scan). It helped the parents to calm down and relax. However, two parents thought that some of the readings had a poor sound quality and therefore choose to listen to similar exercises in other apps that they already had. The audio exercises were not emotionally difficult for the parents to perform, only one parent pointed out that an exercise reminded her of the loss, in a difficult way: *with "Positive visualization"* [exercise] *I tried "Beach"* [exercise] *and it just got really hard. Well because there I have so many memories from it when we have been abroad. But, on the other hand "Forest"*[exercise] *worked, it is like that, different places are so much associated with the grief, then it can be too much* (mother, no. 11).

The writing exercises were the exercises that were most difficult for the parents to perform. They consisted of exercises of exposure, writing a narrative about the loss, and to think about future. Either they were emotionally difficult to complete or the exercises required too much peace and time to perform: *I did not do the writing … it is very difficult to find courage and peace… A lot of thoughts came to mind* (mother, no. 14). Two parents said that they recognized the writing exercises from therapy and therefore did not do them.

Two parents mentioned the reading exercises, which focused on daily activities and feelings. The parents appreciated them and reflected that they would have been especially good early in the grieving process.

Section 4—Get Support

Regarding the section "get support," all parents appreciated this section. The section contained a lot of good information, and it was easy to use because links to web-pages and buttons with phone numbers were integrated. However, most parents did not use the links or numbers. Three parents had long stories during the interviews on how they had searched for this kind of information, year after years, and because of this, many of the parents told that this part of the app would have been useful early in the grieving process, one mother explained: *I have read through all the pages which… paths that you have listed… and that's great, because it was also such thing I thought was very troublesome in the beginning that even, yeah, but where the hell should I turn?* (mother, no 17).

The Overall Use and Experience of the App

Five of the parents used the app more frequently during the first 2 weeks of the study, and then used it less during the last 2 weeks before the interview. Three parents told that they, at first, read through all the parts of the app, then they also tested the self-monitoring section. The self-monitoring and the exercises were used daily by three parents and four of them used them just around one time a week. Two parents expressed that they did not use the app as much as they intended to.

Only one parent had a technical issue with the app when it crashed once. For everyone else, the app worked bug-free and without any errors.

The parents experienced the app as easy to use and clear, giving a calm impression. Three parents told that the green color in the app and the illustrations were very nice to look at. They also appreciated the amount of text. One mother explained: *I think it was really easy to navigate in, it was very easy and like… for me, it* *was very easy to overview and it was nothing, because sometimes… things can be this very long and heavy but it was short, fairly short texts and so you could still move on and so, so I thought it was… no, it was easily accessible* (mother, no.9). However, two parents indicated wanted a clearer overview of the content, menus, and pages in the app because they sometimes got lost in it.

Five of the parents mentioned that the app gave a feeling of their grief being normal, that you are not alone in your grief, and you are not weird or crazy to feel the way that you feel because of the loss: *to feel this… well, I recognize that, then it's not just me who's weird* (mother, no. 11). It created a sense of belonging, and a confirmation that what you do and how you feel is totally okay, which generated a sense of normalization: *I think at least for me, this confirmation that it* [the app] *only exists or that… that an app like this is actually needed says that it's okay to feel the way you do in some way… I think that's the big thing* (mother, no. 24).

However, two parents, who lost their children 6 and 7 years ago, told during the interview that the app could provoke grief and memories again, which was difficult. But what was good was that you could control the use of the app yourself and could choose to shut it down. One parent told that because the app opened up some wounds, it takes time to use all of the app's different sections and its content, more than the 4 weeks during it was tested.

When asked if there was a need for this kind of self-help app for bereaved parents, all parents answered that the app is really needed. That it is good that the app is created and exists, and that the app gives a valuable overview that has been asked for from all the parents during their grieving process. Almost all of the interviewed parents (6/8) wished that the app had existed for them earlier in their grieving process: *I kind of think it's amazing that there will be such an app because there is little support, which sort of comes to you. It's just the Childhood Cancer Foundation, there was nothing in the hospital or connected to that… But it is important that information is provided, that this app exists, because I think it would be a huge help for many parents that lose a child* (mother, no. 9).

Some parents asked during the interview if they got to keep the app after the study was ended, and they were very happy when they knew that they could keep it.

My Grief App-Survey

Nine participants completed the survey questions about the app. The perceived helpfulness of the app was rated moderate or greater by the majority of participants (see **Table 3**). The majority was moderately satisfied or very satisfied with the app overall, while one participant was only slightly satisfied with the app. Seven of the nine participants responded that the app met their expectations. Eight of nine participants did not have any technical problems, while for one person the app crashed once. All nine would recommend the app to parents in a similar situation.

Four participants responded 'yes' on the question "Did you experience any stressful or negative consequences of using the app?" and on the follow-up question on what was most stressful they responded: (1) *It forces out emotions that I repress. Stressful but probably not negative.* (2) *Some formulations were provocative.* (3) *I could not use all the parts, it was too difficult emotionally.* (4) *Stressful not being able to do all the exercises, and not clear how to use the app day by day/step by step.*

Prolonged Grief, Depression, PTSD and Cognitive Processes Related to the Loss

Among 10 participants filling out pre- and post-measures the Wilcoxon paired samples tests indicated that prolonged grief symptoms decreased from pre- to post-assessment ($Z = -2.37$, $p = 0.018$; $d = 0.86$), whereas symptoms of depression ($Z = -1.15$, $p = 0.25$; $d = 0.44$), and PTSD ($Z = -0.97$, $p = 0.33$; $d = 0.26$) did not (**Table 2**). Grief-related rumination ($Z = -1.99$, $p = 0.047$; $d = 0.72$), anxious avoidance ($Z = -2.03$, $p = 0.042$; $d = 0.95$) and negative grief cognitions ($Z = -2.82$, $p= 0.005$; $d = 1.36$) decreased from pre- to post-assessment, while there was no difference on depressive avoidance ($Z = 1.08$, $p=.28$; $d = 0.37$).

DISCUSSION

This pilot study showed that using the My Grief app was feasible and acceptable for bereaved parents. Participants reported satisfaction with the app and stated that they would recommend it to parents in similar situations. According to the participants, the app was easy to use, normalized grief reactions, and gave a valuable overview of information, knowledge, and further support. All four sections of the app were tested by the users, with predominantly positive experiences. The parents also had suggestions on how to improve the app. In addition, all parents expressed that an app like My Grief is needed and that it would be particularly useful to access early in the grieving process. Additionally, our open trial illustrated that access to the My Grief app may reduce prolonged grief symptoms and maladaptive cognitive-behavioral processes in bereaved parents. Notably, among 10 parents, the within-subject effect size was large for prolonged grief, which is comparable with previous studies examining the effect of treatment of PGD (10, 14). For example, Boelen and colleagues (10) reported large within-group effect sizes between pre- and post-treatment ($d = 1.36$–1.80) and Eisma and colleagues (14) reported moderate to large within-group effect sizes ($d = 0.73$–0.92).

When assessing the feasibility of a complex intervention in healthcare, one important part is the recipient's perspective on acceptability and delivery of the intervention (45, 46). Our study illustrated that the content in the app was considered useful, that the app was easy to use, and that it did not cause any harm for the participating parents. However, four parents reported some stressful or negative consequences of using the app such as provocative formulations and that it could be difficult emotionally to use it. It should be noted that confrontational elements, such as exposure, are an integral and effective part of CBT for PGD (10, 14). We therefore considered it necessary to offer exposure exercises to app users. Guidance by a therapist may help reduce the resistance to exposure exercises. An interesting option for future research is to evaluate the use of the My Grief app with therapist support, to help improve the implementation of exposure by participants. Some parents in this study came up with ideas on how to improve the app. Therefore, minor changes

TABLE 3 | My Grief App-survey Scores.

Bereaved parents, $n = 9$	Not at all	Slightly	Moderately	Very	Extremely	Mean (*SD*)
Helping me learn about symptoms of complicated grief	–	3	4	1	1	2.0 (1.0)
Helping me finding effective ways of managing my grief	1	3	4	1	–	1.6 (0.9)
Helping me feel more comfortable in seeking help and support.	1	2	3	3	–	1.9 (1.1)
Helping me feel there is something I can do about my grief	1	1	3	4	–	2.1 (1.1)
Helping me track my grief over time	–	2	5	2	–	2.0 (0.7)
Helping me know when I'm doing better or when I'm doing worse	1	2	4	2	–	1.8 (1.0)
Providing practical solutions to the problems I experience.	1	4	2	2	–	1.6 (1.0)
Helping me better understand my grief reactions	1	1	5	2	–	1.9 (0.9)
Enhancing my knowledge of complicated grief.	–	2	3	3	1	2.3 (1.0)
Providing a way for me to talk about what I have been experiencing.	2	3	3	1	–	1.3 (1.0)

Ratings. 0 = not at all; 1 = slightly; 2 = moderately; 3 = very; 4 = extremely. SD, Standard Deviation.

were made to the app, according to these suggestions, to improve the app before testing it in an RCT. For example, two parents expressed a feeling of "being lost" in the app, and they wanted a clearer overview of where one is in the app. Therefore, small adjustments were made to improve the navigation of the app, by adding a trail of links at the top of the page. Other users expressed a wish for reading more about other bereaved parents, how they coped with the situation and their grief, as well as tips on literature and podcast regarding grief. Therefore, the research group sent out an invitation to the parents that had tested the app after their participation in the study, and asked if they wanted to contribute to the content of the app with their own stories, which were added to the app. Additionally, the research group took the opportunity to adjust certain words in the texts describing grief, labeled as difficult to understand.

Some participants expressed that they did not use the app as much as they intended to, which is in line with other research on self-management smartphone apps for reducing mental illness (25, 47–49). Some of the parents in the current study expressed that the app would have been most helpful earlier in the grieving process. While the purpose of the app was to develop an app for parents with prolonged grief, the findings of this study suggest that parents with lower levels of prolonged grief also benefited from using the app. Therefore, it may be helpful to examine the usefulness of the app as a preventive intervention in future research.

Pilot testing also allows for establishing if methodological issues may arise in a subsequent a larger RCT, such as problems with recruitment, retention and data collection (50). We tested recruitment via the Swedish Childhood Cancer foundation's social media sites. However, during the recruitment process, a substantial minority of parents (8 of 27; 30%) were excluded because of responding "yes" to the question regarding suicidal thoughts. It should be considered that bereaved parents may have thoughts of death without necessarily wanting to commit suicide, which could result in people not receiving access to an app that may be helpful to them. The outcome assessment method is considered to be feasible and not too burdensome, as 13 of 14 participants who consented to participate completed the pre-assessment. Some parents told during the telephone interview that the pre-assessment had been helpful and validated their feelings regarding the loss and the feeling of not being alone in their grief experience. However, three participants dropped out (23%) and did not complete the post-assessment. The drop-out rate of below 25%, has been seen in other studies, such as those evaluating the PTSD Coach, and can be considered acceptable.

While this pilot study has generated promising results, the study has some limitations. First, the small sample size limits the power to adequately detect change over time in all types of symptoms of psychopathology and cognitive-behavioral processes. The non-significant results for small effects on depression and posttraumatic stress symptoms and depressive avoidance appear due to our limited sample size. A larger sample size may have yielded more consistent findings. Nevertheless, it could also be that the relatively low levels of symptoms of depression and posttraumatic stress and the short trial period of 4 weeks led to smaller effects, thereby reducing power. In addition, this pilot study lacked a control group so we do not know whether the changes in prolonged grief and cognitive-behavioral variables were due to access to the app or merely a result of natural recovery over time. However, considering that bereaved parents do not show much natural recovery over extended time-periods (51) we consider it likely that the effects can (at least partially) be attributed to the use of the app. Third, the app was used for a short period and cannot, therefore, completely reflect the intended real-world usage. Some parents expressed that it takes time to thoroughly evaluate the app's different parts, functions, and sections, as well as develop a routine in using the app, e.g., for self-monitoring of grief intensity. The lack of a control group and the short period of time for the users with the app (4 weeks) differs from the design of the larger planned RCT, which includes a wait-list control and app access for 3 months (28). The difference in design was because this pilot-study mainly focused on users' experiences and feasibility of the intervention. Fourth, a majority of the participating parents were highly educated women born in Sweden, so the sample is not representative of all parents who have lost a child. Lastly, we do not know whether the parents who dropped out and did not complete the post-assessment or took part in the interview, were less satisfied with the app than the completers, which may have affected the results.

Despite these limitations, this study offers unique insights. To our knowledge, this is the first study to examine the feasibility of a mobile app for prolonged grief. Additionally, it is the first feasibility study of an app supporting bereaved parents. Our pilot study indicates that the My Grief app is feasible and acceptable. Furthermore, participants showed a reduction in prolonged grief symptoms and most maladaptive cognitive-behavioral variables proposed to prolong grief. Based on the results from the current study, some minor modifications have been made to the app in line with suggestions by the participants and the recruitment process has been slightly modified for a planned RCT testing the effects of the My Grief app.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The study has received ethical approval from the Swedish Ethical Review Authority (project no. 2020-01704). The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

RE, JS, ME, FA, and PB developed the study design. RE and JS performed the analyses and developed the draft of the manuscript. ME, FA, and PB read, revised, and approved the draft of the manuscript. All authors read and approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.872314/full#supplementary-material

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Predictors of Prolonged Grief Disorder in a German Representative Population Sample: Unexpectedness of Bereavement Contributes to Grief Severity and Prolonged Grief Disorder

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Most people adapt to bereavement over time. For a minority, the grief persists and may lead to a prolonged grief disorder (PGD). Identifying grievers at risk of PGD may enable specific prevention measures. The present study examined the extent to which the subjective unexpectedness of the death predicted grief outcomes above and beyond known sociodemographic and objective loss-related variables in a sample drawn from a population-representative investigation. In our sample (n = 2,531), 811 participants (M_{age} 55.1 ± 17.8 years, 59.2% women) had experienced the loss of a significant person six or more months ago. Participants provided demographic and loss-related information, perceptions of the unexpectedness of the death and completed the Prolonged Grief Disorder-13 + 9 (PG-13 + 9). The PG-13 + 9 was used to determine PGD caseness. A binary logistic regression investigated predictors of PGD caseness, and a linear regression predictors of grief severity. ANCOVAs compared PGD symptoms between the groups who had experienced an "expected" vs. "unexpected" loss, while controlling for the relationship to the deceased and time since loss. The loss of a child (OR = 23.66; 95%CI, 6.03–68.28), or a partner (OR = 5.32; 95%CI, 1.79–15.83), the time since loss (OR = 0.99; 95%CI, 0.99–1.00) and the unexpectedness of the death (OR = 3.58; 95%CI, 1.70–7.69) were significant predictors of PGD caseness (Nagelkerke's R^2 = 0.25) and grief severity. Participants who had experienced the loss as unexpected (vs. expected) reported higher scores on all PGD symptoms. Unexpectedness of the death emerged as significant risk factor for PGD, even after controlling for demographic and other loss-related variables. While our findings replicate previous research on the importance of the relationship to the deceased as a risk factor for PGD, they also highlight the importance of assessing the subjective unexpectedness of a death and may help to identify risk groups who can profit from preventive interventions.

Keywords: grief, bereavement, prolonged grief disorder, representative, risk factors, unexpectedness

INTRODUCTION

While bereavement through the loss of a loved one is a highly stressful life event, most people adapt to it over time without professional help (1–3). For a minority of the bereaved, however, grief does not abate and becomes what is termed prolonged grief disorder (PGD). ICD-11 (4) and DSM 5-TR (5) recognize PGD as a distinct mental disorder, though with slightly differing diagnostic criteria. A diagnosis according to ICD-11 requires the presence of at least one of two symptoms of separation distress (persistent and pervasive longing for the deceased or persistent and pervasive preoccupation with the deceased) and a least one of 10 accessory symptoms (e.g., difficulty accepting the death or feelings of guilt in relation to the loss). Additionally, these symptoms must persist to an impairing degree for at least six months after the loss and exceed social and cultural norms of grief. PGD according to DSM-5-TR requires the presence of at least one symptom of separation distress and at least three of eight accessory symptoms to the point of functional impairment in the last month. Additionally, the death of the close person must have occurred at least 12 months ago and symptoms must exceed social and cultural norms of grief (6). Prevalence estimates of PGD vary in accordance with the diagnostic criteria used and the sample under consideration: in recent meta-analyses, its estimated prevalence among bereaved persons ranged from 9.8% (7) to as high as 49%, when considering only persons bereaved by violent losses (8). In our representative study of the German population, the prevalence rate for PGD according to ICD-11 was 1.5% in the overall sample and the conditional prevalence (i.e., among persons having lost a significant other) was 4.2% (9). Compared to the cited meta-analyses, our estimated prevalence rate was relatively low. This could be due to the use of different classification systems (ICD-11 vs. various precursor concepts). More likely, however, differences in the samples under consideration play an important role: Lundorff et al. (7) stressed that most of the original studies included in their meta-analysis did not use a population-based approach with random-selection. Djelantik et al. (8) focused specifically on persons bereaved by unnatural losses. Both factors may be associated with higher rates of PGD than our population-based approach. The present manuscript focuses on PGD according to ICD-11 due to its international applicability and imminent implementation in the German health care system.

In order to inform PGD research and to offer preventive interventions more specifically to groups who are at an elevated risk for PGD and may profit from such treatments (10), it is crucial to identify the risk factors for PGD. Various empirical studies have investigated potential variables that contribute to the development of PGD [for reviews see (11–13)]. In their systematic review of the literature, Burke and Neimeyer (12) included studies in which variables were assessed longitudinally or clearly preceded the loss, were related to the death itself or could be assumed to have remained unchanged since the loss (e.g., gender). They grouped the risk factors into the categories "survivor's background" (e.g., gender), "death- and bereavement-related" (e.g., cause of death), "relationship to the deceased" (e.g., kinship to the deceased), "intrapersonal" (e.g., neuroticism), "religion/belief" (e.g., worldview), and "interpersonal" (e.g., social support). Of all variables investigated, only six were identified as confirmed risk factors for higher grief intensity, i.e., examined in at least three studies and found statistically significant more than 50% of the time. The 32 other variables could only be established as potential risk factors as they did not meet these criteria. This clearly indicates the need for more research concerning the risk factors for PGD. In the present study, we focused on the perception of the death as unexpected as this has been relatively understudied, but could be targeted with an intervention. Ideally, a single study would include all potential predictors; however, this would overtax the participants by the sheer number of questionnaires. Therefore, for the purpose of the present investigation, we included three relatively well-established risk factors as control variables, i.e., female gender (12, 14–16), a closer relationship to the deceased [e.g., being a spouse or a parent (12, 14, 16, 17)], and shorter time since loss (8, 12, 14, 16). Additionally, given the range in our sample, we included age as a control variable. Concerning the age of the bereaved as a risk factor for PGD, meta-analyses and reviews report mixed findings, with two meta-analyses reporting non-significant findings (8, 16), one review reporting a significant negative association (12) and one meta-analysis a negative statistical trend [$p = 0.075$ (7)]. Our primary aim, however, was to examine the extent to which unexpectedness may have incremental validity as a predictor above and beyond the aforementioned variables.

Many studies have reported an elevated prevalence of PGD after sudden and violent losses (i.e., objectively assessed circumstances of the death) (8, 16, 18). In contrast, unexpectedness pertains to subjective experiences of the bereaved person. Perceived unexpectedness may contribute to PGD through several mechanisms. Perceived unexpectedness could hinder grief rituals such as saying good-bye that usually facilitate adaptation to bereavement (19). Unexpected deaths may lead to feelings of being less prepared for the death, which have been shown to be associated with PGD both concurrently and longitudinally (20). Unexpectedness could also increase difficulties in accepting the reality of the loss (21). Deaths that are perceived as unexpected are also less predictable. It has been proposed that since previous research demonstrates that humans prefer predictability, even when associated with negative events, unpredictability could negatively influence the grieving process (22). Based on these theoretical considerations, we expected that unexpectedness would be associated with a greater likelihood of PGD caseness and speculated that it would be more closely associated with certain PGD symptoms such as difficulties accepting the loss, disbelief or avoiding reminders of the loss.

Studies that have investigated the impact of subjective unexpectedness of the death (independently of the objective mode of death) on grief-related distress and PGD have yielded mixed results. A study of recent spousal bereavement reported no significant association between unexpectedness and bereavement outcome (23). In a similar vein, another study found that not being able to anticipate the death of a loved one did not influence pathological grief reactions (22). However, there is also evidence for an association between unexpectedness of the death and bereavement outcomes. Studies have reported that unexpectedness was associated with poorer bereavement outcome in spousal bereavement (24, 25). In samples of participants having lost a loved one due to an illness, greater perceived unexpectedness of the death was positively associated with poorer bereavement outcome (26) and higher PGD severity (27). Focusing on indicators of pathological grief, participants who reported an unexpected (vs. expected) loss reported higher PGD severity in a large Japanese epidemiological study (28). Unfortunately, the latter study excluded specific bereavements [i.e., exclusion of parents having lost a child (28)] and only investigated the respective bivariate relationship, which limits its generalizability. In a recent study focusing on the effects of bereavement during the COVID-19 pandemic, unexpectedness explained differences in pathological grief levels between other natural and COVID-19-related losses (29). Two large studies investigated unexpectedness as a risk factor for PGD severity (30) and a potential PGD diagnosis (31), respectively. In both studies, unexpectedness emerged as a significant predictor, even after controlling for the influence of sociodemographic and loss-related variables.

Unfortunately, the generalizability of many of these results remains limited. First, several studies used convenience samples (24, 27, 29, 30). Although instructive, using such samples cannot take into account the base rate of relevant factors in the general population. The associations between unexpectedness and PGD as reported in the individual studies may therefore be affected or biased by sampling effects. This is illustrated by a recent study which used consistent assessment methods and inclusion criteria across three different convenience samples of bereaved persons to investigate other risk factors for PGD: their general findings could not be reproduced across the samples (32). Second, few studies focus on associations between unexpectedness and PGD as a diagnostic category (28, 31). Most studies report results concerning associations with dimensional outcomes such as PGD severity (22, 27, 29, 30) or grief-related distress (23, 24, 26), respectively. Lastly, the studies used various instruments to assess PGD and PGD severity [e.g., Prolonged Grief-13 (33), Inventory of Complicated Grief (34), Brief Grief Questionnaire (35), Traumatic Grief Inventory Self-Report (36)], which are based on different underlying diagnostic concepts (e.g., prolonged grief disorder, persistent complex bereavement disorder or complicated grief). Since the final criteria for PGD according to ICD-11 have been established only recently, these studies share a common limitation from today's viewpoint: they used various precursors of PGD as outcome and we do not know whether their results generalize to the present diagnostic concept of PGD. Thus, more research is needed concerning the association between unexpectedness of the death and PGD and dimensional grief severity according to ICD-11, respectively, in large, more population-representative samples (35, 37).

The first aim of the present study was to investigate the perceived unexpectedness of the loss as a risk factor for PGD caseness according to ICD-11 in a large sample of bereaved persons drawn from a population-representative study, while simultaneously controlling other risk factors such as sociodemographic variables (gender, age) and loss-related variables (relationship to the deceased, time since loss). We hypothesized that unexpectedness of the death would predict PGD caseness positively above and beyond the sociodemographic and loss-related variables (8, 12, 16). Since many of the previous findings regarding the association between unexpectedness and bereavement outcome relied on a dimensional approach [e.g., (24, 26, 27, 29, 30)], the second aim was to investigate these associations for grief severity. We expected that the same associations with the risk factors would hold true for grief severity as a dimensional variable. Lastly, we wanted to explore whether unexpectedness affects individual grief symptoms differentially.

MATERIALS AND METHODS

Ethics

The institutional review board of the University of Leipzig (Germany) approved the study (145-19/ek, April 2nd, 2019). Potential participants received full information regarding the study purposes and procedures and provided written informed consent.

Participants

This observational, cross-sectional study was conducted as part of a multi-topic survey concerning the physical and mental well-being of the German population, commissioned by the University of Leipzig. A sample, representative of the German population, was collected from May to July 2019. The sampling and data collection proceeded with help of a demographic consulting company (USUMA GmbH, Berlin, Germany).

Inclusion criteria for the multi-topic survey were age ≥14 years and sufficient German language skills. For the sampling, the area of Germany was divided into 258 sample areas representing the whole country. From these areas, households were selected by random route procedure. Within each selected household, one member who fulfilled the inclusion criteria was chosen via the Kish-selection technique. In total, 5,393 valid household addresses were contacted; 2,851 of those contacted failed to provide data for the following reasons: declined participation (household: 22.9%; target person: 12.3%), non-availability after four visits (household: 13.6%, target person: 3.0%), absence of target person (0.6%), and inability of the target person to follow the interview (0.5%).

With the remaining 2,542 participants, face-to-face interviews were scheduled. Trained interviewers (n = 219) informed the participants about the study aims and procedures, obtained written informed consent and collected sociodemographic data. Participants then completed the self-report questionnaire using paper-pencil versions. Interviewers were present until the participant indicated having completed the questionnaire and offered help if the participant did not understand the meaning of a question. Of the resulting 2,542 interviews, eleven could not be analyzed. The sample of the multi-topic survey consisted of 2,531 participants and was representative in comparison to the German micro census with regard to age, gender, and geographic region. The German micro census is a representative survey based on 1%

of the German population [about 810,000 Germans (38)], which is used for political decision making in Germany.

Participants who reported the loss of a significant person six or more months ago and provided PG 13 + 9 data were eligible for the current study. Of the 2,531 participants from the multi-topic survey, 1,720 did not meet these inclusion criteria: not having experienced the death of a significant other (*n* = 1,584), not providing any answers for the PG13 + 9, although they indicated having suffered a loss (*n* = 33), not specifying the time since loss (*n* = 16) and time since loss below six months (*n* = 87). Thus, a total of 811 participants were included in the final sample for the present study. **Table 1** provides the sample characteristics.

Participant ages ranged from 14 to 95 years (mean: 55.1 ± 17.8) with 480 (59.2%) women and 331 men (40.8%). For education, income and further details see **Table 1**. The most common loss was death of a parent (42.4%) (**Figure 1**). The longest time since loss were 1055 months; with a mean of 113.2 ± 123.5 months. For 372 participants (45.9%) the loss was expected, for 355 (43.8%) unexpected and for 82 (10.1%) none/both; two participants did not respond to this item.

Measures

Trained interviewers collected the sociodemographic information using a structured interview. Other data were obtained using self-report questionnaires.

TABLE 1 | Demographic and loss-related characteristics.

Variable	Frequency (%)	Mean (SD)	Valid n
Demographic characteristics			
Age	–	55.1 (17.8)	811
Gender		–	811
Men	331 (40.8%)		
Women	480 (59.2%)		
Education Group		–	790
Primary	554 (68.3%)		
Secondary	126 (15.5%)		
Tertiary	93 (11.5%)		
Other	17 (2.1%)		
Income Group		–	786
<1,250 Euro	308 (38.0%)		
1,250– 2,500 Euro	373 (46.0%)		
>2,500 Euro	70 (8.6%)		
No response	35 (4.3%)		
Loss-related characteristics			
Relationship; deceased person was		–	807
Parent	344 (42.4%)		
Partner	149 (18.4%)		
Child	28 (3.5%)		
Other family member	215 (26.5%)		
Friend	71 (8.8%)		
Time since loss (months)		113.2 (123.5)	811
Unexpectedness of the death		–	809
Unexpected	355 (43.8%)		
Expected	372 (45.9%)		
None/both	82 (10.1%)		

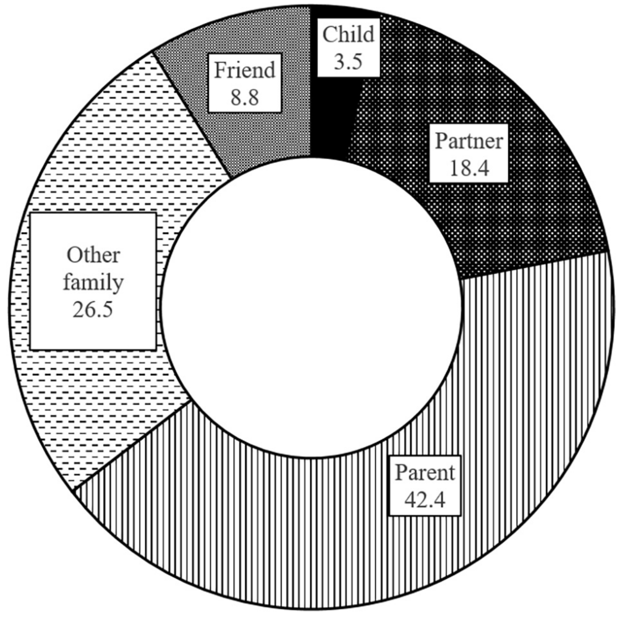

FIGURE 1 | Relationship with the deceased person in percent.

Sociodemographic and Loss-Related Information

Participants provided information on age, gender, education, income and the loss they indicated having suffered including the relationship with the deceased and time since loss. To assess the perceived unexpectedness of the loss, they were asked: "How was your perception of the significant other's death?" with the three answer categories "expected," "unexpected," or "none/both."

Grief Symptoms

Grief symptoms were assessed with the German version of the Prolonged Grief Disorder-13 [PG-13; (33)], which was extended to cover all but one ICD-11 symptoms [the exception was "blame," for a discussion see also (9, 39)]. The resulting PG13 + 9 [PG13 + 9; see (40)] was administered as a self-report questionnaire [for a detailed description see (9)]. Participants rated symptoms on a 5-point scale regarding their frequency (1 = not at all to 5 = several times a day) or intensity (1 = not at all, 5 = overwhelmingly). Grief-related impairment was rated dichotomously as present vs. absent ("Have the symptoms above caused significant impairment in social, occupational or other important areas of functioning?").

Candidates for PGD Caseness

A full diagnosis of PGD can only be made based on a clinical assessment. However, we identified participants who are candidates for a diagnosis of PGD by examining whether participants fulfilled the diagnostic criteria on the basis of their PG13 + 9 answers. For the purpose of the categorical diagnosis, a symptom was treated as "present" if the participant scored ≥ 4 (i.e., present "at least once a day/quite a bit") on the 5-point scale (33). Caseness was determined according to the ICD-11 diagnostic algorithm. The criteria are fulfilled if at least one symptom of separation distress and one or more accessory symptoms are present. The symptoms must be present for at least six months since the loss and be associated with functional impairment [for further detail see (9)]. In our previous study, we found that the diagnostic algorithms of PGD according to ICD-11 and according to DSM-5-TR demonstrated a very high pairwise agreement in our sample [$\kappa = 0.87$; 95% CI: 0.79–0.96 (9)] and only report the result for the PGD caseness according to ICD-11.

Grief Severity

Grief severity was calculated as the sum of the PG13 + 9 score for the items used to determine caseness, with the exception of the item assessing functional impairment. Referring to the German version of the PG13 + 9, this score therefore includes the items 1, 2, 6, 7, 10, 11, 14, 15, 17, 18, and 19 [see (9) for the item match to the ICD-11 criteria]. This resulted in a sum score (with a theoretical range of 11–121) which is used as an indicator for overall grief-related distress.

Data Analysis

In order to test the basic relationships between grief severity and the sociodemographic and loss-related variables, we calculated Pearson correlations between the continuous variables grief severity, age and time since loss. We also calculated *t*-tests (respective Welch tests when the variances were not homogenous) for gender and unexpectedness of the death with the dependent variable grief severity. In order to test grief severity as a function of the relationship with the deceased, we computed an ANOVA followed by Bonferroni *post hoc* tests. As measures of effect size, correlation coefficients, Cohen's d and η^2 are reported.

Two regression analyses were performed with the predictors age, gender, relationship with the deceased, time since loss (in months) and unexpectedness of the loss. The predictors age and time since loss were entered as continuous variables. The nominal variables were dummy coded: Relationship with the deceased with the reference category loss of a parent and unexpectedness with the reference category expected loss. Both regression analyses were calculated blockwise with the method ENTER. In block 1 the demographic variables age and gender and in block 2 the loss-related variables relationship to the deceased and time since loss were entered. In block 3, unexpectedness of the loss was entered to examine whether it explained variance even after the other variables were included in the model. A logistic regression served to establish the predictors for PGD caseness: we calculated a binary logistic regression with the caseness as the criterion (PGD case/no PGD case). Odds ratios (OR) with 95% confidence intervals are reported. A linear regression examined the predictors for the criterion grief severity (as a dimensional score distinct from caseness).

To further investigate whether the participants who had experienced the loss as unexpected differed from those for whom the loss had occurred expectedly, we compared the groups with regard to their grief complaints (excluding participants who had answered "none/both" for expectedness). We used as dependent variables all symptom-level items of the PG13 + 9 included in ICD-11 and conducted a MANCOVA. In order to control for all other factors that contributed to the grief severity in the regression, they were entered as covariates. The MANCOVA was followed by Bonferroni corrected *post hoc* tests.

RESULTS

Descriptive Analysis of the PG-13 + 9 and Bivariate Analyses

The mean PG13 + 9 score (including only the 11 items relevant for ICD-11) was 18.68 ± 8.24. According to the ICD-11 diagnostic algorithm, 38 participants (4.7%) were identified as PGD candidate cases. Among participants reporting the death as unexpected ($n = 355$), 7.0% were identified as potential PGD cases. In the group reporting the death as expected ($n = 372$), 2.7% were potential PGD cases.

In the overall sample, age correlated significantly with the time since loss ($r = 0.19$, $p < 0.01$) and grief severity ($r = 0.09$, $p < 0.05$). Grief severity and the time since loss were associated negatively ($r = -0.16$, $p < 0.01$). Women (19.3 ± 8.6) reported higher grief severity than men (17.7 ± 7.6; $t(761.006) = 2.77$, $p = 0.006$, $d = 0.19$). Grief severity was higher after an unexpected death (20.4 ± 8.9) than after an expected death [16.8 ± 7.3; $t(685.420) = 5.94$, $p < 0.001$, $d = 0.44$]. The ANOVA indicated significant differences for grief severity depending on the relationship with the deceased: $F(4,802) = 24.94$, $p < 0.001$, $\eta^2 = 0.111$. Bonferroni *post hoc* tests showed that participants who had lost a child reported the highest grief severity (28.0 ± 9.8) compared to all other participants (all $ps < 0.001$). Participants who had lost a partner reported the second highest grief severity (22.5 ± 10.2) compared to all other participants except those who had lost a child (all $ps < 0.01$). Participants who had lost a friend (19.2 ± 7.1) showed a higher grief severity than those who had lost a parent (16.8 ± 7.1; $p = 0.016$).

Prolonged Grief Disorder

The blockwise binary logistic regression with the categorical criterion potential PGD caseness showed that the predictors loss of child, loss of partner, and shorter time since loss contributed to the caseness ($\Delta R^2 = 0.165$). When these variables were included in the model, unexpectedness of the loss added a significant increment to the prediction ($\Delta R^2 = 0.042$). The final model explained 25% of the variance. For full detail, see **Table 2**.

Grief Severity

The results for the linear regression predicting grief severity are presented in **Table 3**. The complete model [$F(8,796) = 22.20$, $p < 0.001$] explained 17% of variance, with each of the three blocks contributing a significant increment (**Table 3**) and the same predictors contributing to the grief severity as to the PGD caseness. In block three, unexpectedness explained an additional 4% of the variance in grief severity.

In order to investigate the association between unexpectedness and the individual symptoms, we grouped the participants according to the unexpectedness of their loss (expected vs.

TABLE 2 | Blockwise hierarchical binary logistic regression with the criterion candidate for PGD caseness (PGD case/no PGD case).

	Wald ($df = 1$)	p	OR	OR 95% CI Lower	OR 95% CI Upper	ΔR^2	χ^2	df	p
Model 1[a]						0.045	11.24	2	0.004
Constant	45.98	< 0.001	0.007						
Age	9.54	0.002	1.035	1.013	1.057				
Gender[b]	0.41	0.523	0.798	0.398	1.598				
Model 2						0.165	43.05	5	<0.001
Constant	20.68	< 0.001	0.019						
Age	0.44	0.506	1.009	0.983	1.036				
Gender[b]	0.06	0.810	1.096	0.518	2.318				
Loss of child[c]	27.35	< 0.001	24.458	7.380	81.052				
Loss of partner[c]	11.28	< 0.001	6.212	2.140	18.037				
Loss of other family member[c]	0.01	0.94	0.950	0.258	3.499				
Loss of friend[c]	0.20	0.657	0.615	0.072	5.240				
Time since loss	5.58	0.018	0.995	0.990	0.999				
Model 3						0.042	11.51	1	<0.001
Constant	26.22	< 0.001	0.007						
Age	1.39	0.238	1.017	0.989	1.046				
Gender[b]	0.24	0.876	1.063	0.492	2.297				
Loss of child[c]	23.66	< 0.001	20.297	6.034	68.280				
Loss of partner[c]	9.02	0.003	5.319	1.787	15.831				
Loss of other family member[c]	0.02	0.892	0.914	0.249	3.360				
Loss of friend[c]	0.76	0.382	0.382	0.044	3.308				
Time since loss	7.61	0.006	0.994	0.989	0.998				
Unexpectedness[d]	10.72	0.001	3.582	1.669	7.686				

[a] *χ^2 values and p-values refer to the increments compared to the previous restricted models. The values for the whole models are as follows: Model 2: $\chi^2 = 54.29$, df = 7, $p < 0.001$, Nagelkerke's $R^2 = 0.210$; Model 3: $\chi^2 = 65.79$, df = 8, $p < 0.001$, Nagelkerke's $R^2 = 0.252$; Hosmer-Lemeshow-Tests for all models $p > 0.20$.*

[b] *Reference category: men.*

[c] *Reference category: loss of parent.*

[d] *Reference category: expected.*

unexpected). We then compared the mean severity of individual symptoms between groups with a MANCOVA, entering the variables that were associated with grief severity in the regression (relationship with the deceased, time since loss) as covariates. The MANCOVA yielded effects for the covariates [relationship with the deceased: $F(11, 696) = 11.02$, $p < 0.001$, $\eta_p^2 = 0.148$; time since loss: $F(11, 696) = 7.31$, $p < 0.001$, $\eta_p^2 = 0.104$] and a main effect for the group [$F(11, 696) = 6.98$, $p < 0.001$, $\eta_p^2 = 0.099$]. Bonferroni corrected *post hoc* tests revealed that even after controlling for the relationship with the deceased and the time since loss, the participants who had experienced the loss as unexpected reported higher symptom scores with respect to every individual symptom (**Figure 2**). The effect sizes of all comparisons were small to medium (Cohen's *d*: 0.25–0.45).

DISCUSSION

The present study examined the extent to which the subjective unexpectedness of the death predicted grief outcomes above and beyond known sociodemographic and objective loss-related variables. In our sample drawn from a German population-representative study (9), the following variables significantly increased the likelihood of PGD caseness according to ICD-11: loss of a child or a partner, shorter time since loss and, even when controlling for the influence of all other predictors, perceived unexpectedness of the death. The same variables were also predictors of higher grief severity, when using a dimensional approach. On a single symptom level, the group of participants who had experienced the death as unexpected reported higher scores for each PGD symptom. Our results therefore highlight that in addition to objective risk factors, subjective experiences associated with the circumstances of the death, such as unexpectedness, are important risk factors for PGD.

Our main interest was examining the extent to which subjectively experiencing the death as unexpected was predictive of PGD and grief severity after taking into account known objective predictors. Our results demonstrate that unexpectedness is associated with an elevated risk of PGD and grief severity. This is in line with results from previous studies that have focused on the association between unexpectedness and grief severity (27, 29, 30) and potential PGD caseness (31), respectively. However, it extends this finding to a population-representative sample [in contrast to (27, 29)]. Importantly, and complementing large population-based samples, our study focuses on unexpectedness as a predictor in and of itself [in contrast to combining it with cause of death (41)] and demonstrates the incremental value of unexpectedness

TABLE 3 | Blockwise hierarchical linear regression with the criterion grief severity.

	B	SE	ß	T	*p*	ΔR^2	F	*df*	*p*
Model 1[a]						0.017	6.94	2, 802	0.001
Constant	13.90	1.31		10.60	< 0.001				
Age	0.04	0.02	0.087	2.47	0.014				
Gender[b]	1.60	0.59	0.096	2.73	0.006				
Model 2						0.128	23.76	5, 797	<0.001
Constant	16.90	1.41		12.01	< 0.001				
Age	0.002	0.02	0.004	0.11	0.910				
Gender[b]	0.93	0.56	0.055	1.66	0.096				
Loss of child[c]	11.52	1.51	0.256	7.62	< 0.001				
Loss of partner[c]	5.07	0.83	0.238	6.12	< 0.001				
Loss of other family member[c]	0.23	0.70	0.013	0.33	0.739				
Loss of friend[c]	1.70	1.01	0.059	1.69	0.092				
Time since loss	−0.01	0.002	−0.181	−5.29	< 0.001				
Model 3						0.038	36.98	1, 796	<0.001
Constant	15.12	1.41		10.74	< 0.001				
Age	0.02	0.02	0.032	0.82	0.413				
Gender[b]	0.99	0.55	0.059	1.81	0.071				
Loss of child[c]	10.60	1.49	0.236	7.13	< 0.001				
Loss of partner[c]	4.70	0.81	0.221	5.78	< 0.001				
Loss of other family member[c]	0.10	0.69	0.006	0.15	0.880				
Loss of friend[c]	0.32	1.02	0.011	0.32	0.750				
Time since loss	−0.01	0.002	−0.211	−6.23	< 0.001				
Unexpectedness[d]	3.36	0.55	0.203	6.07	< 0.001				

[a] *F values and p-values refer to the increments compared to the previous restricted models.*

[b] *Reference category: men.*

[c] *Reference category: loss of parent.*

[d] *Reference category: expected; Adjusted* R^2 *for each model: Model 1:* $R^2_{adjust} = 0.015$; *Model 2:* $R^2_{adjust} = 0.137$; *Model 3:* $R^2_{adjust} = 0.174$.

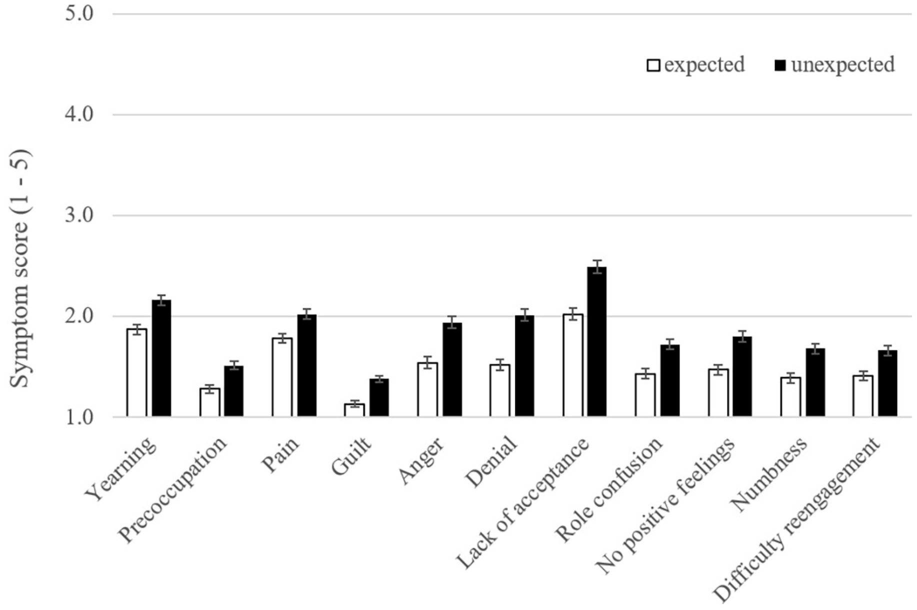

FIGURE 2 | Mean scores of grief symptoms as a function of the expectedness of the loss.

as a predictor over and above other sociodemographic and loss-related variables [in contrast to Deno et al. (28)].

It is interesting to note how widespread the perception of unexpectedness of death was in our sample. This mirrors the results from previous studies, which also reported a high number of deaths perceived as unexpected (28, 31): to illustrate, in a convenience sample of 241 bereaved participants, 55% of the sample reported having experienced the death as unexpected, even though 77% of the same sample reported the cause of death as natural (30). Unexpectedness of the death is a risk factor that will probably become even more relevant in the wake of the COVID-19 pandemic, since COVID-19 related deaths are likely to be perceived as unexpected (42). A recent study investigated acute COVID-19 related bereavement vs. bereavement by other natural or unnatural causes (29). COVID-19 related deaths were indicated more frequently as unexpected (63 vs. 28% after natural deaths) and unexpectedness mediated the effect of cause of death on the acute grief levels of the participants. Since 28% of the natural deaths were experienced as unexpected, these findings also highlight the importance of separating unexpectedness as a subjective perception from the objective cause of death rather than inferring one from the other.

We also investigated whether unexpectedness vs. expectedness of the death affected manifestations of PGD on the symptom level in a bereaved sample. We did not find a specific PGD symptom profile for unexpected losses as has been reported in a sample of bereaved parents (43). This discrepancy could be due to differences in the samples under consideration (representativeness, time since loss, age, and gender) or the different instruments used [Inventory of Complicated Grief (34) vs. PG13 + 9 ICD-11 algorithm]. Future harmonization of the assessment instruments and criteria could certainly help to interpret such discrepancies with more confidence (44). However, participants who indicated that they had suffered an unexpected loss reported higher scores on every single symptom of PGD with small to medium effect sizes. It is important to note that this analysis was not limited to participants meeting the diagnostic criteria of PGD. Its results therefore indicate that unexpectedness is associated with higher grief severity in the absence of a clinical diagnosis (even years after the loss).

One of the most well-established predictors for PGD in the literature is the relationship with the deceased (12, 16). Especially the loss of a child can increase the risk for PGD, as demonstrated across different cultures (14, 45–47). Compared to other losses, losing a spouse or a child seems to convey a considerable risk for PGD [e.g., (14, 47)]. This association was also evident in our analysis, with the loss of a child as the most influential risk factor. Another well-established risk factor is shorter time since loss (8, 12, 16), although a recent meta-analysis did report a non-significant association (7). In accordance with another study that was also based on a German population-representative sample (14), we found that shorter time since loss was a risk factor for PGD among participants whose loss dated back at least 6 months. However, the effect size of the association between time since loss and PGD was relatively small in our sample as well as in other studies [e.g., (14)] and must therefore not be overstated in its importance.

Gender was not a significant predictor for PGD. Our finding concerning gender is somewhat surprising, since being female is considered a well-established risk factor for PGD (12, 14–16). Recent meta-analyses, however, also reported no significant effect of gender on PGD prevalence both after natural and unnatural losses (7, 8). The contradictory findings could be due to the use of different measurement instruments and criteria for pathological grief in the original studies. Additionally, the typical overrepresentation of females in bereavement research (48) may complicate the investigation of gender effects in convenience samples and thus contribute to divergent results. Reflecting the general reliance on convenience samples in the original studies, the meta-analyses are also partly based on studies from convenience samples. Population-representative samples are therefore uniquely relevant to investigate this effect. Interestingly, our finding that gender did not predict PGD is in contrast to the other population-representative studies on PGD conducted so far (14, 41). Among the population representative studies, however, ours is the first to use a diagnostic algorithm of PGD according to ICD-11. It is therefore possible that ICD-11 criteria are less prone to gender effects than previous algorithms. Support for this line of argument comes from a recent registry-sampled cohort study in spousal bereavement (49): using the new ICD-11 criteria and growth-mixture modeling, Lundorff and colleagues demonstrated that all trajectories of prolonged grief comprised similar proportions of men and women. Another recent study, however, reported female gender as a risk factor for PGD according to ICD-11 in three convenience samples (32). Clearly, more research is needed to evaluate the association between gender and PGD according to the current ICD-11 conceptualization.

In our sample, the age of the bereaved person was not a risk factor for PGD, although our sample covered a broad range of ages (14–95 years). While this finding is in contrast to a previous review reporting younger age as a risk factor for more grief-related distress (12), it is in accordance with recent meta-analyses (7, 8). Comparing our result to the other study using a sample drawn from German population-representative sample, the latter study reported older age as a risk factor for PGD (14). Kersting et al., however, investigated the association between age groups and PGD prevalence, not age as a continuous variable and found that participants aged over 61 years were more likely to experience PGD as compared to other age groups. Importantly, the study used age groups with broad spans e.g., grouping participants in the age range from 61 to 94 years into one category. The present study used age as a continuous variable. This is an important difference between the two analytical approaches and possibly affects the results. In addition,—as discussed above with regard to gender—the diagnostic criteria for PGD also differ between the studies. Another possibility is that the relationship between age and PGD could be moderated by circumstances of the bereavement (e.g., kinship with the deceased and time since loss). For example, losing a parent in childhood may be associated with a different bereavement outcome at older age than having experienced the same loss in adulthood. Unfortunately, our study was not powered to assess such moderating effects.

Strengths and Limitations

Strengths of our study are the large sample drawn from a population-representative survey, the use of a well-validated diagnostic instrument to assess PGD with a mapping of the items onto ICD-11 criteria [see (9)] and our analysis spanning cases, syndrome and symptom levels. At the same time, certain limitations must be acknowledged. First, while the sample of bereaved persons was adequately large, the number of potential PGD cases in the sample was lower than reported in previous studies [e.g., (14)]. Our use of ICD-11 criteria and a diagnostic algorithm instead of a cut-off score may explain this discrepancy. Additionally, we cannot make any assumptions with regard to the representativeness of our sample for the bereaved population even though many subgroups of the bereaved were present in our sample (e.g., bereaved parents, widowed persons). The robustness of the risk factors and the generalizability of our results therefore need to be confirmed by further studies. Second, we focused on the subjective experience of the circumstances of the death and did not assess more objective indicators, such as the cause of death. Naturally, the cause of death and the experience of unexpectedness are sometimes interrelated: losses resulting from sudden and violent modes of death (i.e., suicide, homicide, or fatal accidents) are more likely to be experienced as unexpected. Nevertheless, objectively "sudden" deaths, such as suicide, can be experienced as expected [e.g., 46% of participants bereaved by suicide rated the death as expected (50)]. Natural deaths can also be perceived as unexpected (26, 29, 51). Thus, these subjective and objective parameters should not be equated and are each worth consideration. Additionally, a recent investigation corroborates that unexpectedness and cause of death contribute independently to PGD symptoms (52). Therefore, it would be worthwhile to replicate our study with cause of death as an additional predictor. Future studies could also use a continuous measure of unexpectedness. Importantly, our correlative design and retrospective judgment of the unexpectedness cannot exclude that the grief severity affected the reports regarding the perceived unexpectedness. Reporting the death as unexpected may be a consequence of PGD symptoms, rather than a cause of PGD. Nonetheless, reporting that the death was unexpected could still be a useful indicator of the likely presence of PGD. Longitudinal studies could assist in clarifying this relationship. Lastly, while we used a well-established measure of PGD, our PGD assessment was based on a self-report and not a clinical interview by a trained psychologist. The diagnosis of PGD cannot be established on self-report data alone.

Future Research and Implications

Our results have implications for clinical practice and future research. More knowledge about the risk factors for PGD can help to improve the identification of bereaved persons at risk for PGD and to refine grief-specific interventions. Stepped-care approaches or tiered models of bereavement care become increasingly recognized as helpful concepts to guide the development and allocation of support services (53, 54). In order to target and tailor these interventions, reliable information about who is at risk for PGD is necessary. Few previous studies investigating risk factors have used the present ICD-11 criteria for PGD. Our study shows that while some well-established risk factors (e.g., losing a child or a partner) apply also to PGD according to its present definition, other risk factors (such as gender) may need to be re-examined. Future research is needed that uses well-established diagnostic instruments for PGD in its present form and investigates large representative samples and oversamples participants with clinically relevant PGD symptoms. Our data also highlight the potential value of assessing the subjective unexpectedness of the death. Future research on risk factors in PGD that incorporate assessments of objective circumstances of the death and subjective experiences will further our understanding of PGD.

Taken together, our study identified unexpectedness of the death, relationship to the deceased and time since loss as risk factors for PGD according to its current diagnostic criteria (ICD-11) in a sample drawn from a population-representative study. The present findings call into question some previously established risk factors for PGD (e.g., gender), while at the same time corroborating evidence for others (e.g., relationship to the deceased). They also highlight the importance of the perceived unexpectedness of the death as a risk factor for PGD and elevated grief-related distress. This finding is especially important with regard to the current challenges that bereaved persons face during COVID-19 and the identification of persons in need of additional bereavement support.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Review Board, University of Leipzig, Germany. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

RR obtained funding. BD and AB undertook the statistical analyses. BD and AB wrote the complete draft of the manuscript, AV, HC, and RR critically revised the earlier versions of the manuscript. All authors designed the study and contributed and approved the final manuscript.

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From Grief to Grievance: Combined Axes of Personal and Collective Grief Among Black Americans

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In the current article, we argue that the current conceptualization of grief as "the acute pain that accompanies the loss of a loved one" is too narrow in scope. Specifically, our current conceptualization of grief fails to account for the various ways in which grief is manifested amongst Black Americans. Throughout the article, we explore how the history of the racialization of Black people in America has resulted in a unique experience of loss, grief, and bereavement which previous research has largely failed to elucidate. Additionally, we explore how grief catalyzes political and social action. The article also proposes a novel theoretical conceptualization of personal and collective grief to deepen our conceptualization of grief amongst Black Americans. Finally, we posit that we must also consider how to further research on this collective grief to increase our understanding of it and to account for similar phenomena that may exist in communities who've had similar experiences (e.g., Indigenous peoples in the Americas and Dalits in India).

Keywords: grief, Black/African American, collective grief, loss, racism

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INTRODUCTION

In the summer of 2015, 7 days after Sandra Bland was found asphyxiated in her jail cell after being arrested for not using her turn signal, YouTube creator "Evelyn from the Internets" posted a video entitled "Calling in Black" in which she describes the process of waking up to the news of the unjust murder or assault of *another* Black person. She imagines a world in which it is socially acceptable to call in Black to work as one would call in sick (1). In this video, Evelyn utilizes humor to highlight the absurdity of the repetitious violence to which Black people are exposed to whilst, simultaneously, regular life drones on in the background. When describing the various reactions an individual Black person may have to this quotidian violence, Evelyn states "…the other day when I was driving to work and I noticed water randomly pouring from my eyes, I realized something…I was grieving." With over five million views across social media platforms, this skit seems to have tapped into a very relatable experience for Black Americans, and, as we will argue throughout this article , the video explicates a key feature of this experience: grief.

The current conceptualization of grief as "the acute pain that accompanies the loss of loved one" is too narrow in scope to encompass Black grief (2). Specifically, current theoretical conceptualizations of grief fail to account for the various ways in which grief is manifested amongst Black Americans. The racialization of Black people in America has been marked by enslavement, historical and ongoing racial violence, historical and ongoing economic and land dispossession, pervasive structural inequality, and staggering amounts of loss. We must expand our definition of grief to account for the pain that occurs within the Black community after the loss of a loved one, the loss of land, the loss of a sense of safety, and the loss of members of the community due to direct and indirect acts of racist violence. Additionally, we must expand the scope of grief research to consider the experiences of Black Americans through a multisystemic lens that adequately contends with the historical, socio-political, economic, and psychological components that are critical to understanding this unique experience of grief. This article reviews and characterizes the unique and understudied experience of grief for Black Americans, including the unequal distribution of grief, vulnerability to premature death, and historic and ongoing violence. We argue that grief for Black Americans is both different in sheer quantity (because mortality rates are disparate) and qualitatively different (because collective grief is an unstudied but defining feature). This article creates a framework to consider these two axes of grief among Black Americans (i.e., personal and collective grief) and discusses how the inseparable nature of these axes, experienced as a singular phenomenon, can be the motivation for expressing justifiable grievance. We send a call to action for further research to advance the clinical science understanding of collective grief. This may have the future benefit of also increasing our understanding and accounting for similar phenomena in other communities with similar experiences (e.g., Indigenous peoples in the Americas and Dalits in India).

GRIEF IS UNDERSTUDIED IN BLACK AMERICANS

> Grief will always be prolonged, as long as injustice is prolonged.
> —Tashel Bordere, Ph.D.

Grief is typically defined as a primarily emotional reaction to the loss of a loved one through death. It also incorporates diverse psychological (cognitive, social-behavioral) and physical (physiological-somatic) manifestations (2). The loss of a loved one is consistently ranked as one of the most stressful life experiences (3). Cognitive manifestations of grief can include disbelief, yearning, rumination, or difficulty concentrating. Emotional manifestations of grief can include sadness, longing, loneliness, anxiety, sorrow, guilt, anger, and sometimes relief. Physical manifestations of grief can include shortness of breath, feelings of emptiness, muscle weakness, tension, pain, and changes in appetite and sleep (4).

The aforementioned conceptualizations of grief are all individual processes. However, grief can also be experienced communally. Collective grief occurs when a community collectively experiences an extreme change or loss (5). Eisenbruch points out that Western psychiatry has conventionally considered the individual to be at risk, but that attention could usefully be shifted from individuals to an entire uprooted people. In a recent critique of grief research that occurs almost exclusively in the Global North, Stelzer et al. write, "Many cultural factors, working invisibly in the background, affect the way symptoms are expressed, perceived, assessed, interpreted, and documented" (6).

Since the early twentieth century, heavily influenced by Sigmund Freud's "Mourning and Melancholia" (7) essay, the phenomenon of grief has become a topic of study within the field of psychology. Researchers have elucidated many key findings about the common symptoms, coping mechanisms and the mental and physical health outcomes of grief (8). However, Black Americans have largely been underrepresented within research on understanding the psychological impact of grief and bereavement. One recent review found that of the ∼4,000 articles published on grief and bereavement, only ∼100 of these studies included Black Americans in the sample (9).

Within the few dozen studies that have used exclusively Black Americans samples, most have focused on homicide related loss. While it is true that African Americans are more likely to experience the murder of a loved one, the hyper focus on homicide loss has led to a dearth of research on how other types of loss affect this community (9). However, it is important to note that researchers have found that losses that occur without warning or in a traumatic or violent manner (e.g., homicide or suicide), may result in what has been coined traumatic bereavement. Individuals who experience traumatic bereavement must both mourn the loss and cope with the trauma that accompanied the death. Thus, those who experience traumatic bereavement typically experience more intense and severe grief and trauma related symptomology when compared to those who experience a natural death of a loved one (10). A few studies, on the impact of traumatic loss on Black people bereaved by homicide, have found increased rates of PTSD, and "complicated grief" amongst this population and these symptoms may be exacerbated by lack of access to psychosocial services (11, 12). However, these studies were based on relatively small samples and further research is needed to further explicate the true nature of this phenomenon when considering the impact of structural racism.

This lack of representation, plus the prevalent universalist research framework in psychology, has led to a lack of understanding of how the specific contextual factors of living as a Black person, in a Western country like the United States, may differentially impact the experience of grief. Universalism within psychology refers to the idea that the range of human experiences, from basic core needs and psychological processes to core values, are innate and therefore similar across peoples and cultures (13). Although research has shown that a person's ethnicity, social factors, and the geographical and historical context will influence how a person grieves, most psychological research, as Granek notes, "continues to assume that all people can be compared to a universal norm that has historically been based on White, European men" (14). One recent and particularly troubling example of this can be seen in the research supporting the recent inclusion of Prolonged Grief Disorder in the ICD-11. Within the study tasked with the psychometric validation of Prolonged Grief Disorder for the DSM-5 and ICD-11, the sample used data from the Yale Bereavement Study (YBS) which was stated to be 95.3% white. The researchers included no other information about the ethnicity breakdown of the other 4.7% of the sample (15). Despite this overwhelmingly uniform sample, the discussion in the article states "…the YBS sample was 73.7% female compared with 80.7% of the US widowed population and 95.3% white compared with 80.2% of the US widowed population." Despite this glaring difference in the sample and the population, they later concluded the results generalize to most bereaved individuals. However, this conclusion is erroneous. The article notes that the sample is similar to the US population of widows, but the 15% disparity from 80 to 95% in the study sample is one of note. Additionally, the generalized conclusion that PGD is psychometrically valid despite this uniform sample is an example of the prevalence of the universalist framework in psychological science.

One study found that African Americans show a higher prevalence of prolonged grief disorder when compared to white Americans (16). This study also used the same YBS data, and concluded that African Americans have twice the rate of PGD prevalence when compared to whites. These conclusions also stand on shaky ground as these results are based on the assessment of only 66 African American participants (compared to 471 white participants). Additionally, the article further perpetuates the pathologization of Black American experiences and does not critically analyze the lack of representative validation of PGD. The model of decontextualized comparison methodologies combined with the pathologization of grief experiences has been replicated in many studies attempting to understand the Black grief experience (17, 18) and have further contributed to the view of Black Americans as deficient and dysfunctional.

Seeking to understand the experience of grief and its impact on psychological wellbeing is a noble pursuit within the field. However, thus far, a preponderance of the research on grief and bereavement has included samples which are mostly white, middle-aged, middle- or upper-class people. Research that has included Black populations has not adequately contended with the unique contextual factors including culture, racialization, and other factors which shape their grief. There is a great need for more studies that both include more Black Americans in the sample, and all other ethnicities, and specifically assess how ecological systems and cultural factors may influence the specific manifestations of the Black American grief experience. For example, during chattel slavery, enslaved Black people were routinely forced to separate from their spouses, children, and family. These separations were often violent in nature and are generally mentioned when discussing the trauma associated with enslavement (19). However, often overlooked is the grief that accompanies these traumatic losses as well as the reverberating effects across generations. In Solomon Northup's accounts of his time enslaved, he detailed the grief of a woman, Eliza, who had been separated from multiple children. When describing Eliza's separation from her daughter Emily, Northup notes "never have I seen such an exhibition of intense, unmeasured, and unbounded grief" (20). These injuries perdure in the present day as Black families continue to be upended by disproportionate incarceration (21), and disproportionate "child welfare" separations (22). While the experience of death, grief, and loss are universal, the ways in which an individual conceptualizes and subsequently responds to loss are heavily mediated by various social factors, some of which will be explored in the next section.

GRIEF IS NOT EQUALLY DISTRIBUTED

> Racism…is the state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death.
>
> —Ruth Wilson Gilmore, *Golden Gulag*

Disproportionate experiences with grief, loss, and bereavement due to the overlapping and interrelated forces of systemic discrimination and oppression is a defining characteristic of the Black experience in America. The first axis of this experience could be labeled personal grief. According to the 2020 National Vital Statistics report, the average life expectancy for a white American is 78 years and the average life expectancy for a Black American is 72 years; this life span gap increased from the previous year as the average life expectancy for Black American's decreased by 2.7 years due in large part to the unequal distribution of COVID-19 deaths (23). The COVID-19 pandemic death rate for Black Americans is 1.7× higher than white Americans (24), and consequently, Black children were 2.4 times more likely than white children to lose a parent or caregiver (25). In addition to living much shorter lives, Black Americans often live sicker lives. Black American's are twice as likely to die from heart disease than whites, 50% more likely to have high blood pressure, and are more likely to die at early ages from all causes, according to the CDC (26).

However, the consequences of bereavement on surviving grieving family members are a largely overlooked area of racial disadvantage. The statistics above mean that Black Americans have both exposure to deaths of younger family members and friends, and also increased numbers of deaths in their lives. According to a 2017 study, Black Americans are significantly more likely than whites to have experienced the death of a mother, a father, and a sibling from childhood through midlife (27). Before the age of 10, Black children are three times more likely to lose a mother. From young adulthood through later life, Black people are also four times more likely than whites to have experienced the death of a child and twice as likely to experience the death of a spouse (27). The death of a loved one is widely documented as a significant stressor that undermines health and the repeated and early life course exposure to death is unique to Black Americans and has lifelong consequences for relationships and health (28).

Bereavement is a health disparity; these multiple losses have medical consequences. In epidemiological research by Lewis et al., Black women in mid-life who experienced three or more upsetting deaths across 12 years of assessment had greater carotid intima media thickness, a marker of cardiovascular risk measured by ultrasound (29). In addition, although being widowed is associated with significantly higher odds of subsequent death of the surviving spouse across all racial-ethnic groups (e.g., the widowhood effect), the mortality difference by widowhood status is 1.5 times greater among Black Americans (30).

Interpretations of health/death disparity data are often blamed on Black Americans. According to the 2017 "CDC African American Health Report", social factors including higher unemployment rates, higher poverty rates, low home ownership rates, and high obesity rates are to blame for these health disparities. This report neglects to mention the underlying causes of all of the mentioned social factors—racialization and racism. The CDC points to high unemployment rates without including the relevant data on chronically underfunded and under-resourced education systems in Black neighborhoods, or the role of the school to prison pipeline and mass incarceration (21). High obesity rates are incomplete information without including the lack of grocery stores that plague Black neighborhoods, or the fact that Black farmers lost 93% of their land from 1910 to 1997 through racist land dispossession (31, 32). The model of blaming the individual for the manifestations of systemic racism is chronic also within psychological science. In a recent call to action, Volpe et al. (33) noted that psychological science has taken a traditionally ahistorical, acontextual, risk-based, and individual approach to defining and examining concepts of race, racism, and health disparities. This deficit-based individual-level approach implies that psychological science can intervene on racial health disparities by imparting the adequate and appropriate skills and psychoeducation to buffer risk upon Black individuals and communities. However, this framework fails to address the systemic racism that undergirds these observed health disparities or, as Ruth Wilson Gilmore writes in the quotation above: vulnerabilities to premature death.

ONGOING VIOLENCE

> How might we understand mourning, when the event has yet to end? When the injuries not only perdure, but are inflicted anew? Can one mourn what has yet ceased happening?
>
> —Sadiya Hartman, *The Time of Slavery*

While Black Americans are contending with living shorter and sicker lives due to the material manifestations of systemic racism, they are simultaneously exposed to the abuse and death of fellow Black Americans due to racist violence. This chronic exposure to racist violence marks the second axis of grief that is characteristic of the Black American experience—collective grief.

Everyday life is marked by interludes of quotidian racial violence for the average Black American. Whether it be directly experienced (e.g., having a racial slur yelled at you) or indirectly experienced (e.g., waking up to the news of *another* unarmed Black person murdered by police), this commonplace violence is reflective of the normality of racism in the US. These grotesque interludes of violence have been characteristic of the Black American experience since the colonial period. Enslaved Africans were routinely made to witness the horrible acts of violence being done upon fellow slaves. During the Jim Crow era, Black people were routinely brutalized and hung in the public square. In the modern era, social media has introduced a new scale of witnessing to which Black people are subjected. The violence is not limited to local social spheres, but now millions of people can be informed of the latest brutal act of racist violence within minutes (34).

Parasocial grieving is most often used to describe the experience of loss that develops between media users and media personae. Parasocial relationships are one-sided, in which individuals develop an attachment to someone they do not have a personal relationship with, such as a celebrity, a character in a TV show, or an internet personality. Parasocial relationships were first explored in the mid-twentieth century, when Horton and Wohl (35) argued that radio listeners seem to develop intimate bonds with radio personalities that they often listened too. These relationships resemble interpersonal relationships, and prior to social media, parasocial grief was experienced primarily individually or introspectively. However, as discussed by Sanderson and Hope Cheong (36), new media technologies have created the opportunity for individuals to have access to vast social networks consisting of connections across the globe. For example, after the death of singer Michael Jackson, fans were not experiencing the loss of their parasocial attachment alone, but were actively mourning and finding others who felt the same *via* social media networks (36). Thus, social media has created a unique grieving space in which people can connect with others experiencing the same loss across the world.

Previous models of parasocial grief contend a strong attachment prior to the death of a celebrity will lead to feelings of loss or grief (37). However, we posit that the same perceived relationship could be facilitated by intense media coverage of the death of a layperson, especially if there is a connection to the deceased through shared race, gender, or other identity. For example, media exposure to high profile instances of police killings might lead to parasocial grief, especially for Black Americans. The groundwork for intense experiences of parasocial grief, facilitated by new media technologies, was laid throughout the history of racialization of Black people specifically in the U.S context. To understand how parasocial relationships manifest within this community it is important to understand two key features of Black American ethnoracial identity: linked fate and fictive kinship.

Fictive kinship within the Black American community can be traced to the legacy of chattel slavery in the U.S. Fictive kinship can be defined as the extension of kinship or familial obligations and relationships to individuals not otherwise related by blood or marriage (38). Gutman's s classic 1976 work provides vast historical evidence of the practice of establishing fictive kinship ties amongst enslaved Africans in the U.S (39). Guttman revealed that enslaved parents and other adults taught children to address older persons who were unrelated to them by either blood or marriage as "Aunt" or "Uncle". Additionally, due to the nature of family separation and natal alienation during chattel slavery, many enslaved African "replaced" their absent extended family with "fictive kin" with whom they were surrounded. Contemporarily, the family structure of many Black American families often includes non-familial fictive ties. These relationships serve to enhance social control, broaden mutual support networks, and create community (38). Because of this feeling of familial relatedness other Black people, created out of necessity, parasocial grief may be more likely to occur in the Black community following the death of a person who could be family.

In addition, as defined by Dawson (40), linked fate is the recognition that individual life circumstances are inextricably tied to the race as a whole. Linked fate is a feature of ethnoracial identification which begins with a feeling of closeness to others who identify with a group label and evolves into the acceptance of the idea that the individual's life chances are linked to the group. In other words, linked fate is the ever-present awareness that what happens to the group will also affect the individual member. This linkage may also increase the likelihood of parasocial grief within the Black community when a previously unknown Black person is brutally attacked or murdered, because of the feeling that this could be the fate of oneself, or one's brother, son, or father.

Ethnoracial identity has been long considered a protective factor for mental health among Black Americans. However, recent research has suggested that this identification may in fact be a "double edged sword" (i.e., while ethnoracial identification has many positive and protective effects on health, it also has some deleterious effects) (41). One of the ways in which ethnoracial identification can be problematic is through the phenomenon of linked fate. Black Americans disproportionate exposure to the death of a loved one, coupled with the highly visible and broadly reported deaths of Black Americans coalesce to create an overarching sense of threat and distress, especially amongst those whose ethnoracial identification is most salient. While feelings of linked fate can be a powerful source of group mobilization, recent studies have shown that they are also linked to negative mental health effects [see (41, 42)]. As noted by Monk (42), it is key to understand that while a sense of linked fate may have costs to the individual, these costs (e.g., anxiety and anger) may be the fuel to political mobilization.

Linked fate and fictive kinship are two important features of Black American racial identity. Both these phenomena contribute to a greater sense of community interconnectedness *via* shared racial/ethnic identity. This community interconnectedness and racial identification plays a protective role said to moderate the relationship between discriminatory experiences and psychological wellbeing (43–45). These identity markers developed as the result of various aspects of Black racialization in the U.S and have shifted form as social media has created ever larger social networks. However, while these phenomena may have protective elements, their manifestation within the modern world may prove to be a double-edged sword for those whose race/ethnicity is more central to their identity. As Black Americans are already more apt to seeing strangers as close kin and sense their fate is linked to what happens to other Black people, they may be more likely to form parasocial relationships and by extension experience parasocial grief in the digital landscape. Parasocial grief that develops as a result of media exposure to acts like police brutality may, therefore, represent a unique mechanism through which the social stress of discriminatory treatment could exert wide-reaching impacts on the population.

GRIEVANCE

> To be a Negro in this country and to be relatively conscious is to be in a rage almost all the time.
>
> —James Baldwin, *The Negro in American Culture*

While grief is usually conceptualized within the context of loss, the experience is often very generative for the individual or community that has experienced the loss. Perhaps the best way to understand the generative nature of grief is through the word's etymological roots. The word "grief" stems from the Old French *grever* meaning afflict, burden, or oppress, which became the Old French *grief* meaning wrong, grievance, injustice, or calamity. Individuals who experience the loss of a loved one often note experiencing anger because of the acute sense of unfairness or injustice that accompanies the loss of a loved one (46).

Emotions include a signaling function. Anger, specifically, is a natural response to perceived intentional injury, mistreatment, or victimization. It signals the need to increase activity and mobilize efforts to defend oneself or a loved one. The anger and sense of injustice that marks the grief experience makes it a powerful experience with the potential to catalyze efforts to "defend oneself or loved ones" against injustice. This act of resistance and thriving in the face of grief is functional and has both individual- and community-level assets (33).

The catalyzing nature of anger in grief is most readily observed within modern social justice movements. In 1963, four young Black girls were murdered in the bombing of the Birmingham, Alabama 16th Street Baptist Church orchestrated by the local Ku Klux Klan. In his eulogy at the funeral service for the girls, Dr. Martin Luther King, Jr. proclaimed, "... in a real sense they have something to say to each of us in their death...". They say to each of us, Black and white alike, that we must substitute courage for caution. They say to us that we must be concerned not merely about who murdered them, but about the system, the way of life, the philosophy which produced the murderers. Their death says to us that we must work passionately and unrelentingly for the realization of the American dream (47). This call to action was preceded by days of protests at the scene of the bombing, which resulted in the death of two more young Black men killed by the national guard. In his eulogy, Dr. King formalized the grief to grievance process by calling for community members to use the agony from this ultimate injustice, the murder of innocent children, to fuel the continued struggle for human rights. The outrage and collective grief over the death of the four young girls helped to build increased support, particularly from white moderates, of the civil rights movement and desegregation movements. The galvanizing energy from the grief, felt by the nation, for these four girls spurred the reenergized movement that led to the passage of the Civil Rights Act within the next year (1964) and the Voting Rights Act in 1965.

This activating aspect of grief was also on display in the summer of 2020 after the murder of George Floyd in Minneapolis, MN. For 8 min and 46 s, the world watched as Floyd begged for mercy as his murderer held his knee to his neck. Fueled by mass sharing *via* social media, the video of George Floyd's murder was shared and reshared over and over again under the notion of "raising awareness". This collective witnessing, amongst other things, resulted in the largest protest movement in the history of the United States. However, the casual ways in which people consumed his death, and Black death in general, may elicit grief (in addition to trauma and

FIGURE 1 | Examples constituting personal and collective grief axes of Black Americans.

other psychological consequences) in Black people. The outrage over the injustice of Floyd's murder sent shockwaves throughout the world and brought between 15 and 25 million people out into the streets, making the George Floyd protests the largest in U.S history (48). However, these protests were not just displays of anger but also a space of collective mourning and as Judith Butler notes, "…open grieving is bound up with outrage, and outrage in the face of injustice or indeed of unbearable loss has enormous political potential (49)." The George Floyd protests lived up to what Butler (49) describes; political potential and an activated racial reckoning that reverberated throughout all aspects of life in the U.S. Major corporations began to proclaim #BlackLivesMatter, the Minneapolis police department was defunded, and the subsequent conviction of the officer who murdered George Floyd catalyzed countless regular individuals to confront the myth of a post-racial America and commit to fighting for racial justice within their own spheres of influence.

DISCUSSION

The recent pandemic has only amplified bereavement as a health disparity. The consequences of bereavement on surviving grieving family members are largely overlooked in the study of racial disadvantage, and collective grief that includes unique aspects for the Black community, including fictive kin and linked fate, is understudied. The combined mantle of personal and collective grief that Black Americans experience is unrelenting.

As the field of grief and bereavement research continues to grow, we must reckon with the idea that grief exists outside of the accepted definition of "the emotional reaction to the loss of a loved one" in order to incorporate collective and historic grief. We must contend with the myriad ways that grief exists outside of this individualistic, white, western frame. Black people have been traditionally underrepresented in the grief and bereavement research literature. This lack of representation, coupled with a lack of consideration of the unique socio-cultural contextual history of Black people in the west, has left a dearth of understanding of the Black experience of grief. Further, universalist approaches to psychology have led to a further pathologization of Black American grief experiences. Grief research has also failed to interrogate how the disproportionate distribution of bereavement, earlier and more often throughout the life course, might differentially impact Black bereaved people.

By centering our understanding on this more variegated grief, we may find the ways in which it is a strength and therefore change psychological science's Black health narrative. As racialization, and racism (both interpersonal and structural), continues to be an ongoing reality of society, so does the fight for the liberation of oppressed people, including Black Americans. The galvanizing nature of grief is generally showcased on a collective level through things like public memorials or protests in situations of injustice. As the intertwined experience of personal and collective grief catalyzes collective action, which has positive consequences in the sphere of freedom making, it is also important to understand the potentially beneficial and deleterious effects of this phenomenon on the individual level.

Our conceptualization that grief for Black Americans, experienced as an inseparable personal and collective sense, is shown in **Figure 1**. This unique meshing of the personal and collective can catalyze righteous grievance, and this novel conceptualization is largely missing from the literature in grief research today. The potential far-reaching effects of the quantitatively and qualitatively different experience of grief on Black mental and physical health make this an all too important area for future research and analysis.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

DW contributed to the conception and design of theory and brief review of the literature. DW wrote most of the manuscript with M-FO'C contributing to some sections. Both authors contributed to manuscript revision, read, and approved the submitted version.

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BRIEF RESEARCH REPORT
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Restricted Mourning: Impact of the COVID-19 Pandemic on Funeral Services, Grief Rituals, and Prolonged Grief Symptoms

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Background: The COVID-19 pandemic has put various restrictions on grief rituals. Literature suggests that the restrictions on funerals and grief rituals may increase the chance of developing symptoms of prolonged grief (PG). In this study, we explored the possible impact of the pandemic on aspects of the funeral and grief rituals and examined their relationship with PG symptoms.

Method: Bereaved individuals from different countries, who lost a loved one in the year prior to the pandemic ($n = 50$) or during the pandemic ($n = 182$), filled in an online questionnaire, including a rating of the impact of COVID-19 restrictions, five aspects of the funeral service, five aspects of grief rituals, and a measurement for PG symptoms.

Results: Participants bereaved during the pandemic rated the impact of the restrictions on the experience of the funeral and grief rituals as negative. Nevertheless, no differences were found in attendance and evaluation of the funeral and grief rituals for people bereaved prior to vs. during the pandemic. Attendance and evaluation of the funeral services were related to levels of PG symptoms, whereas the performance and helpfulness of grief rituals were not related to these symptoms. Although not related to PG symptoms, half of the participants used helpful alternative rituals to cope with their loss.

Discussion: Our study suggests that bereaved people respond resiliently to the COVID-19 pandemic, for example by creating alternative rituals to cope with their loss. Furthermore, it stresses the importance of looking beyond symptom levels when studying the importance of funeral and grief rituals.

Keywords: COVID-19, bereavement, funeral, rituals, prolonged grief, pandemic, death

INTRODUCTION

Varying across countries and time, the recent COVID-19 pandemic has put various restrictions on engagement in grief rituals, such as not being able to perform religious rites at the bedside, online meetings with the funeral director, limited or no attendees during the funeral service, distance and no physical contact or not being allowed to visit the graveyard or come together for prayers (1). A bereaved individual described the death of a loved one during the pandemic as "a naked death to our culture", because of the absence of grief rituals (2).

Funeral directors have expressed concerns that the absence of rituals could hold "frightening" mental health consequences for bereaved (1). Some bereavement scholars have also raised concerns about the effect that restricted or even absent funerals and grief rituals may have, such as a negative impact on the grieving process and adaptation, and increased chance of developing symptoms of prolonged grief (PG) (3–6). PG symptoms include intense reactions of grief that differ from the social, cultural, and religious norms and persist for a period longer than 6 months after the loss, causing impairment in functioning (7). The time criterion needs to be considered carefully to avoid pathologizing all bereaved individuals. Nevertheless, there are indications that increased PG symptoms early after the loss can predict higher levels of PG 6 month later, which is important to take into account (8).

Empirical findings obtained prior to the pandemic are inconsistent about the relationship between funerals, grief rituals, and grieving reactions. A recent systematic review of quantitative and qualitative studies conducted prior to the pandemic, revealed that most quantitative studies did not find a relationship between funeral practices, such as attendance of the funeral or evaluation of the funeral and grieving reactions (9). Some studies indicated effects for specific aspects of the funeral, such as experiencing the funeral as comforting, or being involved in planning of the funeral, being related to better grief adjustment. And occurrence of adverse events during the funeral being associated with severe grief (10). Two quantitative studies conducted after this review, but prior to the pandemic, did not find a relationship between satisfaction with cremation arrangements or funerals and grief responses either (11, 12). Mitima-Verloop et al. (13) studied the impact of grief rituals performed after the funeral service longitudinally and concluded that the number of grief rituals that people engaged in was not associated with changes in PG symptoms over time. Based on the qualitative studies in their review, Burrell and Selman (9) conclude that the benefit of rituals after bereavement depends on the ability of bereaved people to shape rituals in meaningful ways. Thus, they argue that COVID-19 pandemic restrictions do not necessarily affect grieving processes negatively.

A recurring issue in studies that are conducted prior to the COVID-19 pandemic is the limited variety in the nature, attendance, and evaluation of rituals; most people do attend a funeral or engage in grief rituals and evaluate these positively (13, 14). Moreover, these studies all had participants who made a voluntary decision about participating in a funeral or grief rituals, and were not restricted by circumstances or legislations by governments, such as during a pandemic.

The restrictions during the COVID-19 pandemic offer a new situation to study the importance of grief rituals among bereaved with probably greater diversity in nature, attendance, and evaluation of experiences. Previous studies provide some indications that particular restrictions can negatively impact grief responses (15). For example, a restricted number of people allowed at a funeral service potentially increases family conflict which may lead to adverse events during the funeral, a risk factor for intense grief reactions (1, 10, 11). Thus far, little consideration has been given to possible positive aspects of the COVID-19 restrictions (4).

To date, a few studies have been conducted during the COVID-19 pandemic investigating the association between characteristics of the funeral, grief rituals and grief responses. Menichetti Delor et al. (2) performed qualitative analyses of phone calls with 246 families bereaved due to COVID-19; they reported that mourners expressed a need to perform grief rituals, to find meaning and symbolic ways to say the last goodbye, and to express emotions to cope with the loss. In another qualitative study, based on digital media reports in Brazil, the restrictions on funeral rituals were considered to be a "traumatic experience", causing feelings of disbelief and indignation (16). Hamid and Jahangir (17) concluded, based on 17 interviews with Muslims from Kashmir, that the inability to perform rituals added a layer to the grief, thus affecting the grieving process and overall wellbeing of those affected. In a cross-sectional study among 31 caregivers bereaved due to COVID-19, Bovero et al. (18) found that having the opportunity to attend the funeral was related to absence of complicated grief. Neimeyer and Lee (19) studied a group of 831 United States citizens, bereaved due to COVID-19 and identified several factors related to the pandemic that predispose grief outcomes. Higher endorsement of two items, "feeling upset that the deceased was not given the proper burial or memorial service" and "feeling upset about not being able to say goodbye to the deceased properly" was associated with functional impairment and dysfunctional grief. In contrast, a quantitative study among 114 Turkish bereaved individuals who lost a loved one during the pandemic did not find a relationship between attendance of the funeral or performance of grief rituals and grief reactions (20).

Taken together, most quantitative studies conducted prior to the pandemic demonstrated limited to no association between engagement in and evaluation of grief rituals and grief reactions over time. However, restrictions due to COVID-19 pandemic create a new situation, in which a few studies revealed contradictory results. Therefore, it is worthwhile to investigate the possible impact of the pandemic on various aspects of funeral services and grief rituals, and how this is associated with distressing grief reactions, including symptoms of PG. This may provide valuable information for professionals working with bereaved people. Accordingly, we conducted a cross-sectional survey study in a heterogenous convenience sample of bereaved people, enrolled in different countries.

The first aim of our study was to gain insight in the possible impact of COVID-19 pandemic on various aspects of the funeral service and grief rituals in different countries. It was hypothesized that participants would report a negative impact of the pandemic on their experience of the funeral and grief rituals. By more objective measures, it was hypothesized that individuals who suffered a loss during the pandemic would attend funerals less often, would perform less collective and individual rituals, would evaluate funerals as less positive, and the rituals they would perform as less helpful, compared to participants who lost their loved one prior to the pandemic. In addition, it was expected that

TABLE 1 | Demographics and loss-related characteristics of the sample and group differences ($n = 232$).

Characteristic		Pandemic	Pre-pandemic	Test
		M (*SD*)		*t*-test
Age		37.88 (14.16)	35.46 (14.92)	−1.06
Time since loss (in days)		218 (173.43)	480 (178.87)	9.41**
		n (%)		χ^2
Gender	Male	30 (16.6)	8 (16.0)	0.01
	Female	150 (82.9)	42 (84.0)	
Education	Lower than University	78 (42.9)	9 (18.0)	10.51**
	University or higher	103 (56.6)	41 (82.0)	
Country of origin*	Western countries	124 (68.1)	42 (84.0)	4.85
	Non-western countries	58 (31.9)	8 (16.0)	
Religion	Christian	102 (56.1)	25 (50.0)	3.76
	Muslim	12 (6.6)	3 (6.0)	
	Atheist	23 (12.6)	12 (24.0)	
	Other (e.g., spiritual)	42 (23.1)	10 (20.0)	
Deceased	Close relative (i.e., partner, child, brother/sister, parent)	94 (52.2)	22 (44.0)	0.99
	Other relative/friend	87 (47.8)	28 (56.0)	
Cause of death	COVID-19	49 (26.9)	3 (6.0)	12.81**
	Illness (e.g., cancer)	37 (20.3)	17 (34.0)	
	Natural death (e.g., old age)	27 (14.8)	12 (24.0)	
	Other (e.g., unexpected medical causes, accident)	69 (37.9)	18 (36.0)	

**Participants were born in 32 different countries. Western countries were mostly represented by Greece (n = 55), Germany (n = 47), United Kingdom (n = 26) and Spain (n = 15). Non-western countries were mostly represented by Turkey (n = 31) and Mexico (n = 19).*

***$p < 0.01$.*

participants would perform alternative rituals during COVID-19 pandemic. Our second aim was to examine the relationship between various aspects of the funeral service and grief rituals and the intensity of PG symptoms. Based on previous empirical studies, it was hypothesized that the performance and evaluation of the funeral service and grief rituals would be somewhat, albeit not very strongly, associated with the intensity of PG symptoms.

METHODS

Design and Procedures

A cross-sectional study was conducted using online questionnaires that were distributed between November 2020 and December 2021. Ethical approval was obtained from the Ethics Review Board of the Faculty of Social and Behavioral Sciences of Utrecht University (FETC, 20-0221; 21-2009). The survey was made available in several languages, namely English, Greek, Spanish, German and Turkish. Dependent on availability, validated translations of questionnaires were used and remaining items were translated using forward/backward translation procedures. Bereaved individuals who lost a loved one since 2019 from various, mostly European, countries were invited to participate in the study. They were recruited via convenience sampling methods, such as announcements on social media groups for bereaved individuals, newsletters of funeral organizations, and researchers' personal network. All participants received an information letter and signed informed consent.

Participants

A total of 251 participants completed the online survey. Participants who were bereaved before 2019 ($n = 4$), with unknown date of the loss ($n = 12$), or no complete questionnaires ($n = 3$) were excluded, leaving $N = 232$ participants for the analyses. Their age varied from 18 to 87 ($M = 37.35$, $SD = 14.33$) years. The number of days between the death of the loved one and completion of the questionnaire ranged from 1 through 1,017 days (33 months) ($M = 274.50$, $SD = 205.01$ days). **Table 1** shows additional demographic and loss-related characteristics, for people bereaved before and during the pandemic.

Measures

Socio-demographic variables registered included (i) gender, (ii) age, (iii) level of education, (iv) country of birth, and (v) religious affiliation. Loss-related characteristics included (vi) relationship to the deceased, (vii) cause of death and (viii) date of the loss. A dichotomous variable was created for time of loss, with participants who experienced loss prior to the pandemic (between January 1st 2019 and March 10th 2020) coded as 0 and those who experienced loss during the pandemic (since March 11th 2020) coded as 1. March 11th 2020 was the date the World Health Organization (WHO) declared COVID-19 was a pandemic (21).

PG symptoms were measured with the 18-item Traumatic Grief Inventory self-report version [TGI-SR; (22)]. Participants rated how often they experienced 18 putative markers of PG in the past month (e.g., "I had trouble to accept the loss") on 5-point scales (1 = never to 5 = always). The items of the questionnaire are in line with the DSM-5-TR and ICD-11 criteria of prolonged grief disorder (PGD), with a cutoff score of ≥61 indicating probable PGD. Research has shown good psychometric properties of the scale (23). Cronbach's alpha for the total scale was 0.94 in our study.

Five aspects of the funeral service were measured, namely (i) funeral attendance, (ii) funeral evaluation, (iii) comfort, (iv) planning, and (v) adverse events. (i) To rate funeral attendance, participants were instructed to score the item "Did you attend the funeral of your loved one?" with three possible options, namely "physical attendance", "I did not attend" or "other (such as via livestream/online)". (ii) Evaluation of the funeral was measured using the general evaluation scale of the Funeral Evaluation Questionnaire [FEQ; (13)]. This scale consists of four items, namely "I have been able to say good-bye to my loved one in the best way that was possible", "The way in which the period around the funeral was organized, was important in processing the loss", "I experienced the funeral as sad but positive", and "The good-bye went exactly as I imagined it". Items were scored on 5-point scales (1 = not at all to 5 = very much applicable). Cronbach's alpha for this scale in the present study was 0.80. The last three aspects were added based on the study of Gamino et al. (10), concerning possible factors that influence grief responses, namely (iii) comfort (i.e., "Do you describe the funeral of your loved one as comforting?"), (iv) planning (i.e., "Did you participate in the planning of the funeral?"), and (v) adverse events (i.e. "Were there any distressing or adverse events in connection to the funeral and if yes, how distressing were these events?"). Participants rated to what extent items applied to them on 5-point scales (1 = not at all to 5 = very much applicable).

Five aspects of grief rituals were measured, namely (i) performance of collective rituals, (ii) performance of individual rituals, (iii) helpfulness of collective rituals, (iv) helpfulness of individual rituals, and (v) helpful alternative rituals, based on the study of Mitima-Verloop et al. (13). Participants were instructed to score the item "What grief rituals or activities did you perform?" by selecting yes (scored as 1) or no (scored as 0) for "individual grief rituals in memory of the deceased (carried out alone)" and for "collective grief rituals (carried out with other people)". When "yes" was selected, participants scored the item "How helpful were these activities in general?" for individual and/or collective grief rituals, on 5-point scales (1 = very unhelpful to 5 = very helpful). (v) Participants rated the statement "I found helpful alternative grief rituals to perform" on a 5-point scale (1 = not at all to 5 = very much).

The impact of COVID-19 pandemic on the experience of the funeral and grief rituals was measured using two self-constructed items, namely "Did the restrictions due to COVID-19 have an impact on the experience of (i) the funeral and (ii) grief rituals or activities after the funeral?" Both questions were scored on a 3-point Likert scale with 1 = very negative impact, 2 = negative impact and 3 = no negative impact. Because a pre-pandemic loss might have happened shortly before the date of declaring the pandemic, and engagement in grief rituals often takes place in the months to years after a loss, these questions were answered by all participants. In addition, participants were given the opportunity to explain their answer, with an open ended question. This question was not answered by all participants; some answers were quoted to illustrate findings from the quantitative analyses (see Discussion section).

Statistical Analyses

Statistical analyses were performed using SPSS 27.0 (24). Two participants had one missing value on the TGI-SR questionnaire which were replaced using person mean imputation (25). To address our first aim, we compared participants bereaved before and during the pandemic, in terms of individual characteristics, loss-related variables, aspects of the funeral, and aspects of grief rituals. To this end, descriptive statistics, independent samples *t*-tests, and Pearson's chi-square tests were used. To correct for multiple testing, a significance level of $p < 0.01$ was applied. Regarding our second aim, we compared the groups pre-pandemic and during pandemic on PG symptoms, using descriptive statistics and an analysis of covariance (ANCOVA) to control for time since loss, cause of death and relationship to the deceased. Pearson correlations and point biserial correlation coefficients were calculated to evaluate associations between aspects of the funeral, aspects of grief rituals, and PG symptoms.

RESULTS

The Impact of COVID-19 on Aspects of Funeral Services and Grief Rituals

Bereaved individuals who lost their loved one during the pandemic ($n = 182$) were compared to participants who lost their loved one prior to the pandemic ($n = 50$). Differences were found between level of education, with more people with higher education in the pre-pandemic group (see **Table 1**). Logically, the time since loss was significantly higher pre-pandemic and there were less COVID-19 related deaths reported (although a COVID-19 related death was possible in the days before the WHO declaration of COVID-19 as a pandemic). No significant differences between other demographic variables or loss-related characteristics were found.

Table 2 presents group differences for aspects of the funeral and grief rituals. Participants bereaved during the pandemic rated the impact of the restrictions on their experience of the funeral on average as (very) negative. The impact of the restrictions on the experience of grief rituals was also negative for participants during the pandemic. These scores were significantly more negative compared to the participants pre-pandemic, both for the impact of the restrictions on the experience of the funeral and for the experience of grief rituals, with large effect sizes (respectively $d = 0.75$ and $d = 0.80$).

Despite the restrictions during the pandemic, around 70% of the participants physically attended the funeral of their loved one, while 26.4% did not attend a funeral service. Pre-pandemic, the percentage of participants attending the funeral was higher, although this difference was not significant. No group differences

TABLE 2 | Aspects of the funeral, grief rituals and group differences ($n = 232$).

Characteristic		Score	Pandemic	Pre-pandemic	Test
			n (%)		χ^2
Aspects of the funeral	Attended funeral?	Yes	126 (69.2)	39 (78.0)	1.56
		No	48 (26.4)	8 (18.0)	
		Other	8 (4.3)	2 (4.0)	
			M (*SD*)		*t-test*
	General evaluation (FEQ)	1–20	11.68 (4.57)	12.90 (4.82)	1.47
	How comforting was funeral?	1–5	2.63 (1.25)	2.95 (1.47)	1.40
	Participated in planning of funeral?	1–5	3.20 (1.63)	3.00 (1.52)	−0.68
	How distressing were adverse events?	1–5	2.40 (1.60)	2.00 (1.43)	−1.44
	Did COVID-19 affect funeral?	1–3	1.79 (0.79)	2.69 (0.58)	7.44*
			n (%)		χ^2
Aspects of grief rituals	Performed individual rituals?	Yes	92 (50.5)	26 (52.0)	0.03
		No	90 (49.5)	24 (48.0)	
	Performed collective rituals?	Yes	101 (55.5)	34 (68.0)	2.52
		No	81 (44.5)	16 (32.0)	
			M (*SD*)		*t-test*
	How helpful were individual rituals?	1–5	3.40 (1.05)	3.42 (1.17)	0.11
	How helpful were collective rituals?	1–5	3.33 (1.11)	3.21 (1.18)	−0.56
	Finding helpful alternative rituals?	1–5	2.40 (1.19)	1.77 (1.06)	−3.35*
	Did COVID-19 affect rituals?	1–3	2.04 (0.84)	2.55 (0.65)	3.97*

FEQ, Funeral Evaluation Questionnaire.
$*p < 0.001$.

were found in the general evaluation of the funeral, the level of comfort, the involvement in planning or the level of distress of adverse events connected to the funeral (see **Table 2**).

During the pandemic, half of the bereaved individuals participated in individual rituals and more than half in collective rituals. Both types of rituals were evaluated as somewhat to quite helpful. No group differences were found on ritual performance or helpfulness of the rituals (see **Table 2**). Almost half of the participants (44.6%) indicated that they found helpful alternative rituals to perform (somewhat to very much). Finding helpful alternative rituals was significantly higher among individuals bereaved during the pandemic.

Associations Between Funeral Services, Grief Rituals and PG Symptoms

On average, participants had a total score of 49.26 (minimum = 18, maximum = 85, $SD = 16.31$) on the TGI-SR. People who lost their loved one during the pandemic (estimated $M = 49.94$) had similar symptom levels of PG compared to participants before the pandemic (estimated $M = 46.19$), when controlling for time since loss, cause of death (COVID-19 and unexpected death vs. other) and relationship to the deceased, $F_{(1,\ 225)} = 1.95$, $p = 0.16$. Cause of death and relationship to the deceased were significant covariates. In the whole sample, 61 participants (26.4%) scored above the cutoff score of 61 indicating probable PGD. Of the 146 participants who lost their loved one more than 6 months ago, which is the formal timing criterion for a diagnosis of PGD as per ICD-11 (7), 33 participants (22.4%) scored above the cutoff score.

Table 3 shows correlations between aspects of the funeral, grief rituals, and PG symptoms. Funeral attendance was positively associated with PG symptoms, indicating higher symptoms levels for participants who attended the funeral. General funeral evaluation and experiencing the funeral as comforting were negatively related to PG symptoms, indicating more positive evaluation and more comfort related to less PG symptoms. Experiencing adverse event(s) and participating in planning was both associated with higher PG symptoms. No associations were found between performance and helpfulness of individual and collective grief rituals or finding helpful alternative rituals and PG symptoms.

DISCUSSION

The present study explored the possible impact of the COVID-19 pandemic on various aspects of the funeral and grief rituals in a divers sample of bereaved individuals from different countries. Furthermore, it was examined how these aspects were related to PG symptoms.

Results revealed that participants rated the impact of the pandemic on their experience of both the funeral service and post-funeral grief rituals as (very) negative. Despite this, no significant differences in various aspects of the funeral service and grief rituals, such as funeral attendance, funeral evaluation, and the performance and helpfulness of individual and collective rituals, were observed between participants bereaved before vs. during the pandemic. This is striking, given the numerous restrictions that were put on engagement in grief rituals in

TABLE 3 | Pearson correlations and point biserial correlations between aspects of the funeral service, grief rituals and PG symptoms.

Characteristic		***n***	**PG symptoms**
Aspects of the funeral	Attended funeral? (0 = no, 1 = yes)	221	$r_{pb} = 0.18^{*}$
	General Evaluation (FEQ)	173	$r = -0.20^{*}$
	How comforting was funeral?	172	$r = -0.33^{*}$
	Participated in planning of funeral?	173	$r = 0.31^{*}$
	How distressing were adverse events?	174	$r = 0.27^{*}$
	Did COVID-19 affect funeral?	222	$r = -0.15$
Aspects of grief rituals	Performed individual rituals? (0 = no, 1 = yes)	231	$r_{pb} = 0.07$
	Performed collective rituals? (0 = no, 1 = yes)	231	$r_{pb} = -0.06$
	How helpful were individual rituals?	117	$r = -0.15$
	How helpful were collective rituals?	133	$r = -0.13$
	Finding helpful alternative rituals?	221	$r = -0.02$
	Did COVID-19 affect rituals?	219	$r = -0.13$

PG, Prolonged Grief. Funeral attendance is taken as a dummy variable, in which the answer "other" was disregarded.
r, Pearson correlation, r_{pb}*, point biserial correlation.*
$^{*}p < 0.01$.

countries all over the world (1). Apparently, the negative impact that participants experienced did not directly indicate less attendance or a negative evaluation of the funeral and grief rituals they engaged in. The non-significant difference in funeral attendance might be due to the fact that, in relation to the duration of the pandemic, the period and number of countries in which intimate family members were not or hardly allowed at funerals was relatively short. Furthermore, it is possible that different factors were connected to the negative impact of the restrictions, which were not considered in our study. For example, literature points toward the lack of social support from more extended family and friends who were not able to participate in the funeral due to restrictions (26).

These results might also suggest that bereaved individuals acknowledged that the restrictions had a major negative impact on their experiences, but also appreciated the funeral service as positive because it was the best way possible at that time. It is a well-known aspect of human judgment to evaluate situations to a reference point, and not in isolation (27). In the comment section of our questionnaire, participants described for example how grateful they were for the minimal support they received, how they experienced more solidarity and support because of the difficult circumstances, and how individual rituals such as lightning a candle helped them to grief their loved one alone. This is reminiscent of prior observations that, when adversity strikes a large group, the shared experience can have positive effects (28). During the pandemic, participants were more able to find helpful alternative rituals to perform. This outcome is consistent with previous qualitative studies conducted during the pandemic, reporting how people were able to create alternative rituals and creative new strategies to remember and grieve their loved ones (1, 29). These findings connect well with Burrell and Selman's (9) conclusion, that the benefit of rituals depends on the ability of bereaved individuals to shape rituals in such a way that is meaningful to them.

A considerable number of participants reported high levels of PG symptoms, even 6 months post loss. Symptom levels of PG were especially high among those bereaved after an unexpected death (including COVID-19) and those having had a close relationship to the deceased. This corresponds to previous studies, underlining the concern that the pandemic will lead to a higher prevalence of grief disorders [e.g., (30)].

Different aspects of the funeral were related to PG symptoms. However, the directions were not always as expected, and all correlations were small. The positive association between funeral attendance and PG symptoms could be explained by the fact that during the pandemic, often only close relatives were allowed to physically attend the funeral, and a close relationship to the deceased is a common factor related to more intense grief (31). Interestingly, this result differs substantially from the study of Bovero et al. (18), which included a very specific sample of bereaved individuals due to COVID-19 in the first wave of the pandemic in Italy. The great diversity of restrictions across time and across countries should be taken into consideration while comparing studies. Being involved in planning of the funeral was also related to higher PG symptoms, likely because involvement overlaps with being in a closer relationship with the deceased. An alternative explanation could be that funerals have been planned without the support of others due to restrictions on social contact (26). Further studies could focus more on characteristics of those attending in relation to other aspects of the funeral such as comfort and funeral evaluation.

Although associations between aspects of the funeral and PG symptoms were weak, these findings are interesting as they differ from the results of the longitudinal study of Mitima-Verloop et al. (13). In contrast to aspects of the funeral, and in line with Mitima-Verloop et al. (13), engagement in collective and individual rituals, their helpfulness, as well as performing alternative rituals were not related to PG symptoms. Besides looking at symptom levels of grief, further studies should focus on other aspects to get a better understanding of the impact of grief rituals. For example, Becker et al. (12) showed that dissatisfaction with the funeral was related to higher costs spent on medical and welfare services. Ritual elements, gaining more attention in therapeutic grief interventions, serve different functions and intensions, and their impact should therefore be measured in a broad sense, including concepts such as meaning and recognition (32–34). In addition, future studies could investigate the importance of cultural and religious values in relation to COVID-19 and grief, as restrictions led to major discrepancies between religious rituals, values, and government regulations (35).

Several limitations of this study should be mentioned. First, the study included a heterogeneous sample from different countries and in different times during the pandemic. Therefore, the results may not all apply to specific groups under specific circumstances during the pandemic. Furthermore, because of the convenience sampling methods, there is a possibility of response bias (e.g., underrepresentation of individuals with intense grief reactions). Nevertheless, a strength of the present study is that it extends previous research by including various aspects of the funeral service and grief rituals. In addition, the unique situation created by the COVID-19 pandemic led to greater diversity in engagement and experience of the funeral and grief rituals and therefore stronger measurements.

In conclusion, despite the negative impact of restrictions due to COVID-19 that many bereaved experienced, this impact seemed limited on engagement in and evaluation of funerals and grief rituals during the entire period of the pandemic. Associations were found between negative funeral experiences and symptom levels of PG, although these associations were weak. Besides the negative aspects, COVID-19 restrictions may also bring some positive aspects, such as experiencing more close connections because of the difficult circumstances and the possibility to create meaningful alternative rituals. Our results underline the resilience of individuals and the importance to look beyond symptoms when studying the importance of funerals and grief rituals.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The study was reviewed and approved by the Ethics Review Board of the Faculty of Social and Behavioral Sciences of Utrecht University. The participants provided their informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

HM-V and PB conceptualized and designed the survey and study. MK was involved in data collection and data analyses. HM-V drafted the manuscript. PB and TM provided critical feedback to the draft manuscript. All authors reviewed and approved the final version of the manuscript.

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A Latent Class Analysis on Symptoms of Prolonged Grief, Post-Traumatic Stress, and Depression Following the Loss of a Loved One

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Background: The loss of a significant other can lead to variety of responses, including prolonged grief disorder (PGD), posttraumatic stress disorder (PTSD), and depression. The aim of this study was to replicate and extend previous research that indicated that three subgroups of bereaved individuals can be distinguished based one similar post-loss symptom profiles using latent class analysis (LCA). The second aim was to examine whether sociodemographic and loss-related characteristics as well as the extent of meaning making were related to classes with more pervasive psychopathology.

Methods: Telephone-based interviews with 433 Dutch and German speaking persons who had lost a significant other at last 6 months earlier were conducted. Self-rated PGD, PTSD, and depression symptoms were assessed. LCA was conducted and correlates of class-membership were examined using the 3step approach.

Results: The LCA resulted in three distinct classes: a no symptoms class (47%), a moderate PGD, low depression/PTSD class (32%), and a high PGD, moderate depression/PTSD class (21%). A multivariate analysis indicated that female gender, a shorter time since loss, an unexpected loss and less meaning made to a loss were significantly associated with membership to the moderate PGD, low depression/PTSD and high PGD, moderate depression/PTSD class compared to membership to the no symptom class. Losing a child or spouse, a shorter time since loss, and having made less meaning to the loss further distinguished between the high PGD, moderate depression/PTSD symptom class and the moderate PGD, low depression/PTSD class.

Discussion: We found that the majority of individuals coped well in response to their loss since the no symptom class was the largest class. Post-loss symptoms could be categorized into classes marked by different intensity of symptoms, rather than qualitatively different symptom patterns. The findings indicate that perceiving the loss as more unexpected, finding less meaning in the loss, and loss-related factors, such as the recentness of a loss and the loss of a partner or child, were related to class membership more consistently than sociodemographic factors.

Keywords: prolonged grief, PTSD, depression, latent classes, meaning making

INTRODUCTION

In the face of the death of a significant other, people react differently toward their loss. Grief can take up many forms, often including yearning, sadness, and difficulties experiencing positive emotions. The majority of those who experienced a loss resume daily routines and retake part in social or occupational activities within a couple of months and adjust well (1). For others, adjustment is more difficult and grief reactions may take up the form of prolonged grief disorder (PGD), depression, and/ or, in the face of a loss due to traumatic circumstances, posttraumatic stress disorder (PTSD) (2–5).

Factors accounting for maladjustment to loss are manifold. Sociodemographic factors, such as female gender or lower level of education, play a role in the development of PGD, depression and PTSD, while factors inherent to the death and the deceased such as a close kinship to the deceased, and a shorter time since the death were more consistently shown to be associated with PGD (6–8). A violent or sudden nature of the loss has been demonstrated to be associated with PGD, PTSD and depression (9, 10). The way a bereaved person cognitively processes a loss can have an enormous impact on their adjustment. Meaning-making refers to the capacity of an individual to integrate the loss into their belief system about the world and themselves, and to find an explanation or even growth in the loss (11, 12). It has repeatedly been shown that a greater extent of meaning-making is associated with better adjustment to loss as evidenced in lower rates of PGD, depression and PTSD (11, 13–15). Although these cognitive factors have the potential to be targeted in treatment, they are less often investigated (6).

After decades of research and considerable debate (3, 16, 17), PGD was introduced as diagnostic entity in the 11th version of the International Classification of Diseases (ICD-11), which has come into effect on January 1st, 2022. ICD-11 PGD is characterized by separation distress defined as longing or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g., sadness, guilt, anger, or difficulty accepting the death) (18). A diagnosis can be made when the above-mentioned symptoms last for more than 6 months and exceed the social, cultural, or religious norms of the individual's culture or context. While the related concept "Persistent Complex Bereavement Disorder" (PCBD) was included only as condition for further study (section III) within the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the American Psychiatric Association added prolonged grief disorder in section II in its newest DSM-5-TR edition published in March 2022 (19, 20). PGD shares several features with PTSD and depression and has been shown to be often comorbid, particularly in the wake of violent losses (6, 21). Yet, evidence similarly exists that PGD constitutes a specific syndrome, with separation distress representing a unique feature that is not captured by other disorders (22–25).

To diverge from the notion of examining how disorders do or do not overlap using diagnostic algorithms, some researchers have explored how symptoms of PGD and other indicators of mental health co-occur in bereaved individuals using latent class analysis (LCA). Latent class analysis is a person-centered statistical approach that finds subtypes of related cases in empirical data and thus explores whether there are subgroups of individuals that endorse similar symptom profiles (26). The majority of previous research on PGD using LCA included only two mental health indicators (e.g., PGD and depression or PGD and PTSD) (27, 28). Only a few studies exploring latent classes of PGD and other indicators of mental health included all three mental health indicators PGD, PTSD, and depression. Most LCA studies found three classes: a no symptom class marked by low probabilities to endorse symptoms, a high distress class marked by high probabilities to endorse all PGD, PTSD, and/or depression symptoms, and a PGD class marked by high probabilities to endorse symptoms specific to PGD (29–31).

Moreover, previous studies on LCA mostly relied on the DSM-definitions of the examined disorders. However, definitions of PGD/PCBD and PTSD in ICD-11 vs. DSM-5 differ from each other with regard to the number and content of the symptoms (18, 32). Research has shown that the overlap between the respective definitions is not optimal and that prevalence rates were higher for ICD-11-PGD than for DSM-5 PCBD (33–36). Findings obtained with one definition of a disorder may thus not necessarily apply to another definition of the disorder.

In the light of the ICD-11 coming into effect, aim of this study was to replicate and extend previous findings by examining latent classes of PGD, PTSD, and depression symptoms in bereaved people using the ICD-11 definitions of the disorders. Based on prior LCA studies in bereaved people, we expected to identify at least three latent classes: a (1) low symptom, (2) PGD only, and (3) high symptom class (29–31). Our second aim was to examine correlates of class-membership. We expected that people in the classes with more pervasive symptomatology were more likely to be female, less educated, to make less meaning of their loss, and more likely to have experienced an unexpected or violent loss (29, 31).

METHOD SECTION

Procedure

This cross-sectional study is part of a longitudinal study on TGI-CA Assessment after Loss in Europe (TALE project), which focuses on the development and validation of an instrument to assess a grief disorder as defined in ICD-11 and DSM-5(-TR) (18, 20). For more information about the study and measures used see https://osf.io/a6hmc/. The study is a joint project at the University of Twente, Groningen, Utrecht, and the Freie University Berlin. It was approved by the Ethical Committee of Psychology of the University of Groningen and the Freie University in Berlin. Data were collected between November 2019 and September 2020 through structured telephone interviews. The breakout of the COVID-19 pandemic occurred after interviews with about 300 participants had already been conducted. We continued our efforts to assess data nonetheless. Pandemic-related restrictions may thus have an effect on part of our data. Interviews were conducted by Dutch and German psychologists (all B.A.) who had received a training on the phenomenology and theoretical background of PGD, the use of questionnaire measures, and interview techniques. This study was pre-registered on the Open Science Framework (see https://archive.org/details/osf-registrations-6hzxw-v1).

Participants

Participants were recruited through a convenience sampling approach with the help of self-help organizations, mourning cafés, and hospices. In addition, advertisements were placed on social media as well as in the student pool of the respective universities to recruit participants. Interested participants signed up for the study online and provided their informed consent. They were then contacted by the interviewer to schedule a date for the interview. Participants did not receive financial compensation; however, first year psychology students received course credits for taking part in the study. Inclusion criteria required participants to be 18 years or older and to have lost a significant other (i.e., spouse, family member, or friend) at least 6 months prior to the interview. Exclusion criteria were the presence of a psychotic disorder and acute suicidal ideation assessed with single items in the interview. Interviews took about 45 min to complete. A total of 448 participants were recruited ($n = 221$ Dutch speaking, $n = 227$ German speaking). Interviews were not completed with six participants because they fulfilled exclusion criteria. Moreover, nine people were excluded from data analysis as their most significant loss had occurred < 6 months ago, resulting in a final sample size of $N = 433$.

Measures

The following background and loss-related characteristics were assessed: gender, age of participant, educational level, number of losses, kinship to the deceased, time since loss, cause of loss (i.e., physical illness, accident, suicide, murder/manslaughter, other), unexpectedness of loss (1-5; 1 = totally not unexpected, 5 = completely unexpected), meaning made to the loss [i.e., "To what extent would you say that you were able to give meaning to your loss?"(11) (1 = no meaning through 4 = a good deal of meaning)], history of general psychological support (i.e., "Did you ever receive support for your own problems prior to the death of your loved one from a psychologist, therapist or psychiatrist?" 0 = no, 1 = yes), and received professional bereavement care (i.e., "Did you ever receive support from a psychologist, therapist or psychiatrist related to the death of your loved one?," 0 = no, 1 = yes).

Traumatic Grief Assessment—Clinician Administered

PGD symptoms were assesses using the TGI-CA. The 22-item TGI-CA was developed in the context of the TALE project and is based on 22-item Traumatic Grief Inventory-Self Report Plus (TGI-SR+; 37). The English, German, and Dutch translation of the TGI-CA are freely available *via* the Open Science Framework (https://osf.io/a6hmc/). The TGI-SR+ is a reliable and valid survey to assess PGD symptoms in terms of ICD-11 and DSM-5-TR (37). The TGI-CA deviates from the TGI-SR+ in two aspects: (1) in the TGI-SR+ items were phrased as statement, while in the TGI-CA items were phrased as questions, and (2) in the items and instruction of the TGI-SR+ we refer to "deceased loved one," while in the TGI-CA we replaced this wording with the first name (e.g., "Albert," "Mary") or relationship (e.g., "your husband") of the deceased person. Participants who reported more than one loss were asked to specify which loss was most distressing or most often in their mind and to relate their answers on the TGA-CA to that loss. Participants rated how often they experienced each symptom during the past month with 1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = always. PGD according to ICD-11 criteria is measured using the 12 items that correspond to the ICD-11 classification, namely TGI-CA items 1, 2, 3, 5, 8, 9, 10, 16, 19, 20, 21, 22. Internal reliability in the current study was high ($\alpha = 0.90$).

PTSD Checklist for DSM-5

PTSD symptoms were measured with the Dutch and German version of the PCL-5, a 20-item self-report screening instrument that corresponds to the DSM-5 symptoms of PTSD (38–40). Items are rated on a five-point Likert scale from 1 (not at all) to 5 (extremely). In accordance with previous research (34, 41), six items approximating the ICD-11 operationalization of PTSD were selected to tap ICD-11 PTSD. These items included item 2 (repeated, disturbing dreams), 3 (feeling or acting as if the experience were happening again) 6, (avoidance of internal reminders), 7 (avoidance of external reminders), 17 (being "superalert," watchful or on guard) and 18 (feeling jumpy, easily startled). Cronbach's alpha levels in the current study was 0.68.

Patient-Health-Questionnaire-9

Depression was assessed using the Dutch and German versions of the Patient Health Questionnaire [PHQ-9; (42–44)]. The PHQ-9 is a dimensional screening instrument consisting of nine items based on the diagnostic criteria of depression according to DSM-5. Participants are asked to indicate the severity on a four-point Likert Scale from 1 (not at all) to 4 (almost every day). Internal consistency for the PHQ was 0.80.

Work and Social Adjustment Scale (WSAS)

The 5-item Work and Social Adjustment Scale (WSAS) was used to measure functional impairment (45–47). People rated on 9-point scales with anchors 1 = not at all through 9 = severely to what extent the death of their loved one impaired them in their (i) work, (ii) household chores, (iii) social activities, (iv) leisure activities, and (v) close relationships. We added the answer option "not applicable" to the item referring to work. The WSAS demonstrated good internal consistency ($\alpha = 0.80$).

Statistical Analysis

Dichotomized item scores of PGD, PTSD, and depression were used as indicators in the LCA. Following prior research (48, 49), the five-point Likert scale of the ICD-11 PGD items of the TGI-CA and ICD-11 PTSD items of the PCL-5 were dichotomized by treating a score of 1 and 2 as symptom absence and a score of 3, 4, and 5 as symptom presence. For depression the four-point Likert scale was recoded by considering a score of 1 and 2 as symptom absent and a score of 3 and 4 as symptom endorsed (48).

The fit of a 1-class through 6-class model was compared using statistical and non-statistical criteria. Model preference relied on a lower (Sample-Size Adjusted) Bayesian Information Criterion (SA-BIC and BIC) and Akaike's Information Criterion (AIC), bootstrap likelihood ratio test (BLRt) with a *p*-value of <0.05, (3) higher entropy R^2 value, (4) not too small class sample sizes, and (5) accordance with prior LCA research. In case statistical fit indices were indecisive, we relied on the BIC (50). When interpreting LCA symptom profiles, we considered a symptom presentation probability of <0.15 as low, a symptom presentation probability of ≥ 0.15 and ≤ 0.59 as moderate, and symptom presentation probability of ≥ 0.60 as high (27). The statistical program LatentGold was used for the LCA (51).

For descriptive purposes we included the total scores on PGD, PTSD, depression, and functional impairment as separate correlates in the model to examine to what extent the classes differed in terms of these severity levels. We did so by using the 3step-approach in LatentGold, which takes the classification error into account when examining correlates of class-membership. We calculated 95% confidence intervals (95% CIs) for class-comparisons. When zero was not included in the 95% CIs the class-comparisons were considered significant.

Correlates of class-membership were examined using again the 3step approach. The following correlates were included simultaneously in a multinomial logistic regression analysis: gender (0 = male, 1 = female), age (in years), educational level (0 = primary, high school, vocational school, 1= university), number of losses (0 = 1 loss, 1 = multiple losses), kinship to the deceased (0 = other than child/spouse, 1 = child/spouse), time since loss (in years), cause of loss (0 = natural, 1 = unnatural), unexpectedness of loss (1-5; 1 = totally not unexpected, 5 = completely unexpected), meaning made to the loss (1 = no sense through 4 = a lot of sense), history of general psychological support (0 = no, 1 = yes), and received professional bereavement care (0 = no, 1 = yes). Based on Chi-square tests and correlation analyses, there was no concern for multicollinearity. Maximum of five responses (1.2%) were missing on the indicators. These missing data were handled using full information maximum likelihood estimation. Missing data on the correlates were handled using listwise deletion. A maximum of one response was missing per correlate.

RESULTS

Participants

Table 1 displays the sample characteristics. The sample consisted of 352 female (81.3%) and 81 male participants (18.7%). The mean age was 43 years (SD = 16.89; range: 18-86). The majority of participants indicated having been born in either Germany (*n* = 214, 49.9%) or the Netherlands (*n* = 192; 44.5%). About half of the participants had a university degree as their highest educational attainment (*n* = 216; 49.9%) and about both a quarter indicated high school (*n* = 113; 26.1%) or a vocational education (*n* = 101, 23.3%) as their highest educational attainment.

Loss-Related Variables

More than half of the participants reported having experienced multiple losses. When asked whose loss was the most difficult to cope with, *n* = 130 (30.0%) reported the loss of a parent, *n* = 119 (27.5%) the loss of their partner, *n* = 73 (16.9%) the loss of a grandparent and *n* = 51 (11.8%) the loss of their child. The average time since the most significant loss was M = 6.7 years (SD = 8.2, range = 6 months-60.7 years). About 20% of the participants had lost their significant other to violent causes and half of the participants indicated that the death of their significant other came "very" or "completely" unexpected. Moreover, 43.9% reported that they had made no or little sense to their loss.

Latent Class Model Fit

The fit indices for the one through six class models are shown in **Table 2**. When increasing the number of classes, the AIC and SA-BIC values kept decreasing and all entropy R^2 values were acceptable (>0.80). The BLRt showed that the two class model showed a significantly better fit than the 1 class model. All other BLRt *p*-values were >0.05. The BIC value was lowest for the three class model. The three class model showed symptom patterns that accords with prior LCA research in bereaved people (29, 52). We therefore selected the three class model as optimal solution.

Latent Classes of PGD, PTSD, and Depression

See **Figure 1** for probability estimates of the three class model. Figures for other latent class models are displayed in the **Supplementary Material**. The largest class consisted of 204 individuals (47%) and was characterized by low probability of endorsement of PGD, PTSD, and depression symptoms, except for two PGD symptoms and two depression symptoms that had moderate probability. We labeled this class the "no symptom class." The second class included 139 people (32%) and was marked by moderate to high probability of endorsement of PGD symptoms and low to moderate probability of endorsement of PTSD and depression symptoms. This class was named "Moderate PGD, low depression/ PTSD class." The third and smallest class comprised 90 people (21%) that had high probability of endorsement of 8 out of 12 PGD symptoms and moderate probability of all PTSD symptoms and moderate probability for five out of nine depression symptoms. We labeled this class the "High PGD, moderate depression/ PTSD class." The probability estimates and standard errors are shown in **Supplementary Table 1**.

The three classes differed significantly in severity levels of PGD, PTSD, depression, and functional impairment, such that the "no symptom class" <

TABLE 1 | Sociodemographic and loss-related characteristics (*N* = 433).

Gender				
	Female	*n*, %	352	81.3%
	Male	*n*, %	81	18.7%
Age		M, SD	43.1	16.9
Education				
	Primary school	*n*, %	3	0.7%
	High school	*n*, %	113	26.1%
	Vocational Education	*n*, %	101	23.3%
	University	*n*, %	216	49.9%
Multiple loss (yes)		*n*, %	234	54,2%
Kinship to most significant loss				
	Partner	*n*, %	119	27.5%
	Child	*n*, %	51	11.8%
	Parent	*n*, %	130	30.0%
	Sibling	*n*, %	16	3.7%
	Grandparent	*n*, %	73	16.9%
	Friend	*n*, %	19	4.4%
	Other	*n*, %	25	5.8%
Cause of death				
	Natural loss (e.g., illness, old age)	*n*, %	334	77.1%
	Unnatural loss (e.g., suicide, accident)	*n*, %	99	22.9%
Expectedness of loss				
	Totally not unexpected	*n*, %	106	24.5%
	A bit unexpected	*n*, %	72	16.6%
	Quite unexpected	*n*, %	44	10.2%
	Very unexpected	*n*, %	63	14.5%
	Completely unexpected	n, %	147	33.9%
Meaning made to the loss				
	No sense	*n*, %	130	30.0%
	A little sense	*n*, %	60	13.9%
	Quite a bit of sense	*n*, %	108	24.9%
	A lot of sense	*n*, %	135	31.2%
Time since loss in months		M, SD	80.4	98.0

M, mean; SD, standard deviation.

TABLE 2 | Fit indices for the latent class models.

	LL	BIC (LL)	AIC (LL)	SABIC (LL)	Entropy R^2	BLRt p-value	Class sizes
1 class model	−5563.47	11290.84	11180.93	11205.16			433
2 class model	−4746.19	9826.27	9602.38	9651.73	0.92	0.054	296/137
3 class model	−4603.75	9711.37	9373.5	9447.98	0.84	0.160	204/139/90
4 class model	−4521.14	9716.12	9264.27	9363.87	0.84	0.236	211/95/66/61
5 class model	−4468.08	9779.99	9214.16	9338.88	0.84	0.268	186/104/54/46/43
6 class model	−4423.76	9861.33	9181.52	9331.37	0.83	0.348	154/108/52/42/41/36

AIC, Akaike Information Criterion; BIC, Bayesian Information Criterion; BLRt, Bootstrapped Likelihood Ratio test; LL = Loglikelihood; SA-BIC, sample size adjusted Bayesian Information Criterion.

"moderate PGD, low depression/ PTSD class" < "high PGD, moderate depression/ PTSD class" (see **Table 3**). See **Supplementary Table 2** for estimates and 95% CIs.

Background and Loss-Related Correlates of Classes

Correlates of classes were entered simultaneously into the model. Results are displayed in **Table 4**. Compared to the "no symptom

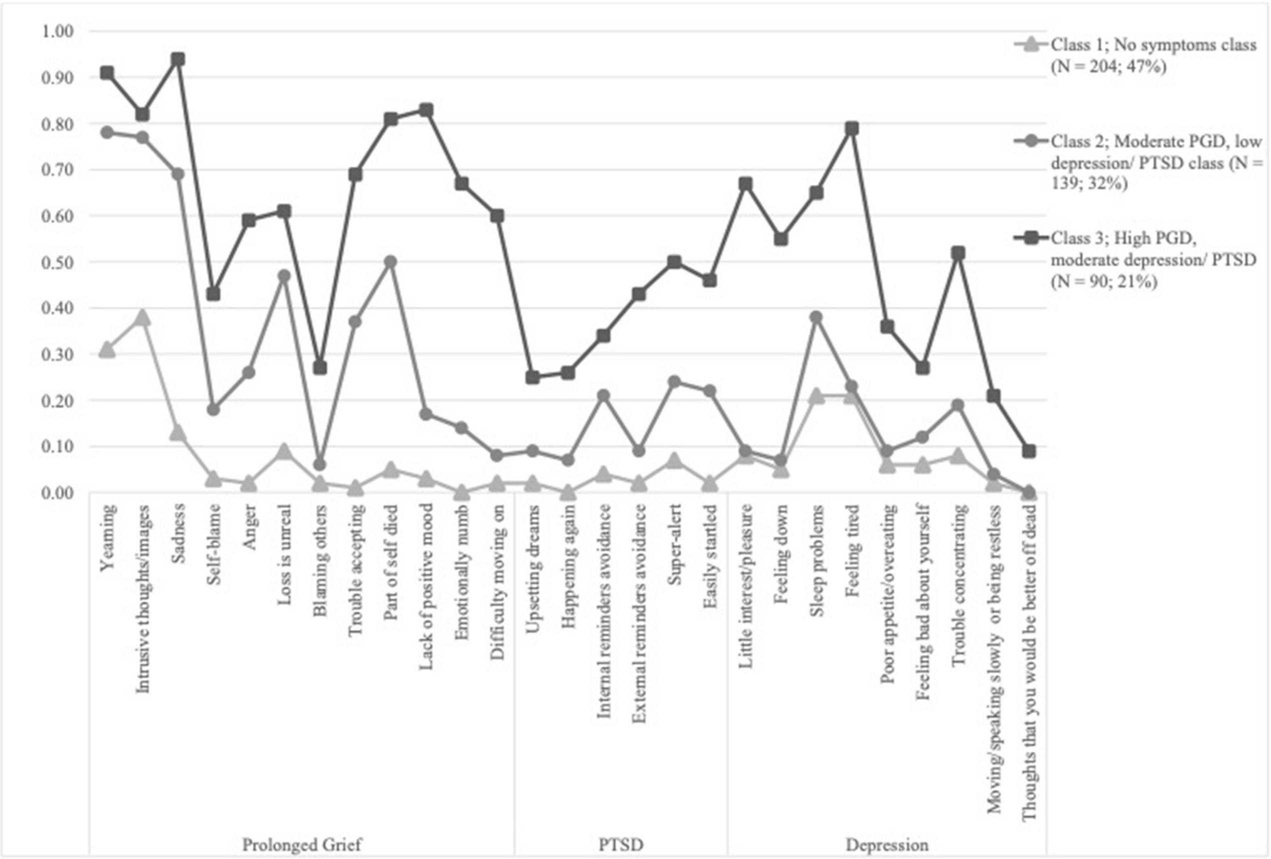

FIGURE 1 | Probability estimates of the three class solution (*N* = 433).

TABLE 3 | Univariate associations between PGD, PTSD, depression, and functional impairment levels and classes (*N* = 433).

	Total sample	No symptom class *n* = 204 (47%)	Moderate PGD, low depression/PTSD class *n* = 139 (32%)	High PGD, moderate depression/PTSD class *n* = 90 (21%)	Pairwise comparisons (Class)
PGD levels, M (SD)	23.54 (9.02)	16.37 (2.86)	25.78 (4.76)	36.32 (7.07)	1 < 2 < 3
PTSD levels, M (SD)	9.28 (3.35)	7.25 (1.53)	9.71 (2.40)	13.21 (3.84)	1 = 2 < 3
Depression levels, M (SD)	15.53 (4.57)	13.32 (3.18)	14.86 (3.07)	21.56 (3.90)	1 < 2 < 3
Functional impairment levels, M (SD)	17.71 (8.87)	13.57 (7.20)	18.92 (7.86)	25.20 (8.33)	1 < 2 < 3

PGD, Prolonged Grief Disorder; PTSD, Posttraumatic Stress Disorder.

class," membership to the "high PGD, moderate depression/PTSD class" was associated with female gender, the loss of a child or spouse, less time since the loss occurred, unexpectedness of the loss, and less meaning made to the loss. Equally relative to the no symptom class, membership to the moderate PGD, low depression/PTSD class was more likely for female participants, those whose loss had occurred more recently, those who experienced their loss as more unexpected and those who had made less meaning of their loss. Moreover, members of the moderate PGD, low depression/PTSD class were more likely to have received bereavement care than members of the no symptoms class. Lastly, compared to the moderate PGD, low depression/PTSD class, membership to the high PGD, moderate depression/PTSD class was associated with the loss of a child or spouse, less time since the loss, and less meaning made to the loss. Estimates and 95% CIs are presented in **Supplementary Table 2**.

DISCUSSION

This study examined latent classes of PGD, PTSD, and depression symptoms in a sample of Dutch and German bereaved individuals using the ICD-11 definitions of the disorders. The

TABLE 4 | Correlates of class membership in multivariate model.

	No symptom class *n* = 204 (47%)	**Moderate PGD, low depression/ PTSD class *n* = 139 (32%)**	**High PGD, moderate depression/PTSD n = 90 (21%)**	**Pairwise comparisons (Class)**
Gender (1 = Female), *N* (%)	155 (76.0)	119 (85.6)	78 (86.7)	1 < 2 =3
Age (in years), M (SD)	42.39 (17.60)	42.35 (16.03)	45.66 (16.49)	1 = 2 = 3
Educational Level (1 = University), *N* (%)	105 (51.5)	74 (53.2)	37 (41.1)	1 = 2 = 3
Kinship to the Deceased (1 = Child/Spouse), *N* (%)	62 (30.4)	53 (38.1)	55 (61.1)	1 = 2 < 3
Cause of Loss (1 = unnatural), *N* (%)	36 (17.6)	32 (23.0)	31 (34.4)	1 = 2 = 3
Number of Losses (1 = multiple losses), *N* (%)	114 (56.2)	70 (50.2)	50 (55.6)	1 = 2 = 3
Time Since Loss (in years), M (SD)	8.41 (8.94)	4.39 (5.57)	4.19 (8.63)	1 > 2 > 3
Unexpectedness of Loss (1-5; 1 = totally expected, 5 = completely Unexpected), M (SD)	2.82 (1.61)	3.29 (1.60)	3.78 (1.49)	1 < 2 = 3
Meaning Made to the Loss (no meaning through 4 = a good deal of meaning), M (SD)	2.93 (1.14)	2.49 (1.18)	1.90 (1.11)	1 < 2 < 3
History of general psychological Support (1 = yes), *N* (%)	85 (41.7)	66 (47.5)	44 (48.9)	1 = 2 = 3
Received professional bereavement care (1 = yes), *N* (%)	67 (32.8)	71 (51.1)	50 (55.6)	1 < 2, 1 = 3; 2 = 3

findings of the current study were broadly in line with previous LCA findings using the DSM definitions of the disorders regarding the number of extracted classes and the factors associated with classes with more pervasive psychopathology.

The LCA revealed that a three-class solution fitted the data best. The largest class was termed no symptoms class and comprised almost half of the participants. It was characterized by low item probabilities for almost all PGD, PTSD, and depression symptoms. The moderate PGD, low depression/PTSD class included a third of the participants and was characterized by low to moderate item probabilities for the PTSD and depression symptoms and moderate to high item probabilities for the PGD symptoms. The smallest class, labeled as high PGD, moderate depression/PTSD class, included the remaining 21% of the sample and was marked by high item probabilities for the majority of PGD and three of the depression symptoms and moderate item probabilities for the PTSD and remaining depression symptoms. A three-class solution is consistent with the majority of LCA studies including PGD, PTSD, and depression symptoms (29, 52, 53). However, while previous LCA studies on PGD found classes that were separable by both severity and quality (or "type") of symptoms (30, 53), classes in the present study differed merely by the severity of symptoms. This indicates that in the current sample, there was no particular PGD response, but rather a high comorbidity of PGD with PTSD and depression within the more symptomatic classes. Members in the high PGD, moderate depression/PTSD class, had, among other symptoms, high probabilities to experience the PGD symptoms "sadness," "lack of positive mood," and depression symptoms "little interest/pleasure" and "feeling tired." These symptoms overlap in content and may thus contribute to higher comorbidity. On the other hand, items indicative of negative sense of self-worth or blame (i.e., items "blame," "self-blame," or "feeling bad about oneself") had low probabilities across all classes. These observations might support previous research that symptoms centering around specific themes are connected across syndromes (49). While some LCA studies found a particular PTSD class (27, 54) it seems plausible that PTSD classes rather emerge in studies with survivors who have been confronted with both loss and trauma in the context of war or forced displacement.

We also tested the differences in PGD, PTSD, functional impairment and depression scores across the classes. The average severity of PGD, PTSD, depression and functional impairment was highest in the high PGD, moderate depression/PTSD class, followed by the moderate PGD, low depression/PTSD class and was lowest in the no symptom class. Only the average PTSD scores did not differ significantly between no symptom and moderate PGD, low depression/ PTSD classes. We thus concluded that the classes were distinguishable meaningfully.

The second aim of this study was to examine the relationship of several sociodemographic and loss-related factors with class membership. In this study, the subjective perception of the loss (i.e., perceived expectedness and meaning made to the loss) and loss-related factors (such as time since loss and relationship to the deceased) predicted class membership more consistently than sociodemographic factors (such as age, gender, education). More specifically, the extent to which participants had made meaning of their loss and the recentness of the loss distinguished between all classes and having lost a child or spouse additionally distinguished between the moderate PGD, low depression/PTSD and high PGD, moderate depression/PTSD class, while age and education were found to be unrelated. Our finding that the extent of meaning made to the loss clearly distinguishes between the classes is in line with previous findings that showed that less meaning made to a loss was associated with more PGD symptoms (55). This has important implications for clinical practice. Compared to sociodemographic or loss-related factors that are invariant (e.g., gender, relationship to the deceased) or systemic in nature (e.g., time since loss), reconstructing meaning can be addressed in treatment and thus facilitate adjustment. A meaning reconstruction approach through writing assignments and a ritual of remembrance may be a promising intervention to finding meaning and reducing PGD symptoms (56, 57). However, future research should also investigate whether meaning making is indeed a constructive coping strategy that results in "actual" meaning-finding or rather the result of a cognitive bias that also contains illusory aspects (58).

In addition to recentness of the loss and meaning making, having perceived the loss as unexpected, having received professional grief support, and female gender distinguished between the no symptom and the moderate PGD, low depression/PTSD class. Contrary to our hypothesis, the cause of the loss was unrelated to class membership when taking other covariates into account. Our findings suggest that in the current sample, it was rather the subjective perception of the loss (expected vs. unexpected) than the objective cause (violent vs. non-violent loss) that was associated with adverse mental health outcomes. Cause and unexpectedness of death are related constructs as most violent deaths are unexpected and it might be that in our sample, cause did not explain unique variance beyond the unexpectedness of a loss. This accords also with prior findings that an objective measure of unexpectedness (measured as "number of days between forewarning of death and the actual death") was not associated with PGD symptoms (59), while a subjective measure of perceived unexpectedness was linked to elevated levels of PGD symptoms (60, 61). Further recent research demonstrates that bereaved persons who experienced their loss as unexpected reported higher levels of PGD, even when other variables were controlled (62, 63).

It is a promising finding that among the more symptomatic classes, more than half had sought professional grief support, potentially indicating positive attitudes toward professional help within the current sample. However, half of them did not seek grief support which points again to a treatment gap in bereavement care which has also been identified in prior research (64). It seems conceivable that individuals who had developed symptoms after their loss were also more likely to seek professional grief support. There is some evidence highlighting potential barriers to seeking mental health care among bereaved people, such as thinking the problems will naturally disappear, pain of talking about the loss, and difficulty finding help (64, 65). These two prior studies on barriers to seek support were conducted in people bereaved by traffic accidents and parents who lost a child due to cancer. It would be desirable for future research to examine these barriers in people bereaved by other causes. Finding out about these barriers to professional grief support may entail important knowledge how to approach individuals in need of mental health care, particularly in light of the inclusion of PGD in the ICD-11, which enables evidence-based treatment covered by health insurance.

Limitations

Some aspects should be discussed that may impact the interpretation of results. Data for the current study were gathered before and during the breakout of the COVID-19 pandemic and the pandemic-related restrictions and additional stressors are likely to have had an impact on the well-being of our participants. Research to date has focused primarily on the negative consequences of the pandemic for adults who have suffered a loss due to the virus or during the pandemic (66, 67). Less is known about the impact of the pandemic on the grief intensity of people who have experienced a loss before the pandemic (68). It is possible that social isolation and the respective lack of social support, increased worries about oneself and relatives have increased the mental health burden. For others, the pandemic may also have had a positive effect by providing more time to process a loss. It would be desirable if future research addressed the specific impact of the pandemic on the grief process of the bereaved.

A few limitations should be considered when interpreting the results. Data for the current study were gathered in telephone-based interviews. Even though interviewers were trained, it is possible that differences in data assessment between telephone and in-person administration exist. For example, telephone-based interviews may enable participants to talk more openly about their distress, but misunderstandings due to the lack of transmission of non-verbal cues are possible. Second, we used a selection of PCL-5 items to assess ICD-11 PTSD. Although the PCL-5 is a validated instrument to assess PTSD for DSM-5, it was not developed to assess ICD-11 PTSD. However, items in the PCL-5 are mostly congruent and equivalent in content with the formulation of items within the International Trauma Questionnaire, an instrument specifically developed for the assessment of ICD-11 PTSD (69). Third, different guidelines for interpreting probability estimates have been suggested (27, 70). For the purpose of comparability, we used cut-off scores that are most commonly used in the field of latent classes of PGD. These interpretation guidelines have a relatively low threshold to consider the probability of a symptom as "moderate" or "high." Similarly, we followed other LCA research (28, 29) by using the three highest answer options on the TGI-CA as symptom presence. For the aforementioned reasons, a possible risk of pathologizing scores should be considered. Fourth, expectedness of loss and meaning making were assessed with one item, respectively. Future research could use multi-item or more observational instruments to assess these constructs, for example the *Grief and Meaning Reconstruction Inventory* (71). Fifth, despite our efforts to include male participants in our study, female participants predominate this sample by far. Results can thus not be generalized to a male sample. Some evidence suggests that male forms of grief may be different, e.g., that socially constructed ideals may encourage stoic behavior or expression of grief as anger (72, 73). Even though it seems challenging, future research should increase efforts to include men in grief-research to a gender-balanced level. Last, the cross-sectional nature of this study does not allow to draw conclusions about the causal relationship between variables.

CONCLUSION

In conclusion, LCA revealed three subgroups differing in symptom severity of PGD, PTSD, and depression in a large sample of Dutch and German bereaved individuals. While the majority of bereaved individuals coped well in response to their loss, results show that women, those who had lost a close relative recently and unexpectedly and those who expressed difficulties to make meaning of their loss had a higher probability to show psychological symptoms, in particular PGD and depression.

In cases of more pervasive psychopathology, addressing meaning reconstruction in treatment might be an important pathway to help bereaved individuals to integrate the loss into their world view. More than half of participants in the more pervasive symptom classes received professional grief support, which can be interpreted as an encouraging indication of the openness toward professional support among those in need of help.

DATA AVAILABILITY STATEMENT

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found at: https://osf.io/a6hmc/.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Freie University Berlin and University of Groningen. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CH and LL are responsible for the study design and concept. Data were assessed by CH, MF, HH, and LL. LL undertook the statistical analyses. CH and LL drafted the manuscript, which was critically revised by CK, HH, and MF. All authors contributed to and have approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.878773/full#supplementary-material

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