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Prolonged grief, post-traumatic stress, and functional impairment in parents and siblings 8 years after the 2011 Utøya terror attack

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ABSTRACT

Background: Research on bereavement after terrorism is limited and primarily aiming on short-term consequences.

Objective: To better understand the long-term health consequences of terrorism, we studied bereaved parents and siblings eight years after the Utøya terrorist attack in Norway. We examined the participants' symptom levels of prolonged grief (PG) and post-traumatic stress (PTS), as well as their psychosocial functioning and employment status.

Method: Bereaved parents ($n = 88$) and siblings ($n = 34$) aged 19 and above (mean age = 49.7 years, $SD = 13.8$ years, 59.8% female) completed the Inventory of Complicated Grief (ICG), the Impact of Event Scale-Revised (IES-R), and the Work and Social Adjustment Scale (WSAS) to assess PG, PTS, and functional impairment, respectively. In addition, information about employment status was obtained. The proportion of participants scoring above recommended thresholds on the ICG, IES-R, and WSAS was calculated. Differences between parents and siblings and gender differences on these measures were examined.

Results: In total, 62.3% of the participants had scores on the ICG indicating a risk for prolonged grief, while 45.9% scored over cutoff on the IES. There was a high overlap between symptoms of PG and PTS. Females had significantly higher scores on both the ICG and the IES compared to males. There were no differences between parents and siblings regarding PG and PTS symptoms. One out of three showed severe functional impairment on the WSAS. Approximately 30% of all the bereaved were outside the labour force, and one third of the parents had become unable to work after the terrorist attack.

Conclusion: Many bereaved parents and siblings, following the Utøya terror attack, report long-lasting health consequences with symptoms of PG and PTS and functional impairment. The results suggest a need for follow up of bereaved after a terror attack and identify family members in need of health services.

Duelo prolongado, estrés postraumático y deterioro funcional en padres y hermanos, 8 años después del ataque terrorista de Utøya de 2011

Antecedentes: La investigación sobre el duelo después del terrorismo es limitada y apunta principalmente a las consecuencias a corto plazo.

Objetivo: Para comprender mejor las consecuencias del terrorismo en la salud a largo plazo, estudiamos a padres y hermanos en duelo, ocho años después del ataque terrorista de Utøya en Noruega. Examinamos los niveles de síntomas de duelo prolongado (DP) y estrés postraumático (EPT) de los participantes, así como su funcionamiento psicosocial y situación laboral.

Método: Los padres en duelo ($n = 88$) y los hermanos ($n = 34$) mayores de 19 años (edad media = 49,7 años, $DE = 13,8$ años, 59,8% mujeres) completaron el Inventario de Duelo Complicado (ICG, por sus siglas en inglés), la Escala revisada de Impacto del Evento (IES-R, por sus siglas en inglés) y la Escala de Adaptación Laboral y Social (WSAS, por sus siglas en inglés) para evaluar DP, EPT y deterioro funcional, respectivamente. Además, se obtuvo información sobre la situación laboral. Se calculó la proporción de participantes con puntajes superiores a los umbrales recomendados en ICG, IES-R y WSAS. Se examinaron las diferencias entre padres y hermanos, y las diferencias de género en estas medidas.

Resultados: En total, el 62,3% de los participantes obtuvo puntajes en el ICG que indicaban un riesgo de duelo prolongado, mientras que el 45,9% obtuvo puntajes superiores al límite en el IES. Hubo una alta superposición entre los síntomas de DP y EPT. Las mujeres obtuvieron puntajes significativamente más altos tanto en el ICG como en el IES en comparación con los hombres. No hubo diferencias entre padres y hermanos con respecto a los síntomas de DP y EPT. Uno de cada tres mostró un deterioro funcional severo en WSAS.

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PALABRAS CLAVE

Duelo; Duelo traumático; Duelo prolongado; Estrés postraumático; Deterioro funcional; Terrorismo; Situación laboral; Hermanos; Padres

关键词

丧亲; 创伤性哀伤; 延长哀伤; 创伤后应激; 功能受损; 恐怖主义; 就业状况; 兄弟姐妹; 父母

HIGHLIGHTS

- Eight years after the Utøya terrorist attack bereaved parents and siblings still report high levels of prolonged grief and post-traumatic stress symptoms.
- There were no differences between parents and siblings regarding prolonged grief and post-traumatic stress symptoms.
- Many bereaved are still suffering functional impairments. Post-traumatic stress symptoms are found to be an important predictor for functional impairments.

Aproximadamente el 30% de todos los familiares en duelo estaban fuera de la fuerza laboral, y un tercio de los padres no pudieron trabajar después del ataque terrorista.

Conclusión: Muchos padres y hermanos en duelo, luego del ataque terrorista de Utøya, reportan consecuencias de salud duraderas con síntomas de DP y EPT y deterioro funcional. Los resultados sugieren la necesidad de un seguimiento de los dolientes después de un ataque terrorista e identificar a los miembros de la familia que necesitan servicios de salud.

背景：关于恐怖主义后丧亲的研究有限，且主要针对短期后果。

目的：为了更好地了解恐怖主义对健康的长期影响，我们在挪威于特岛恐怖袭击发生八年后研究了丧亲的父母和兄弟姐妹。我们考查了参与者的延长哀伤 (PG) 和创伤后应激 (PTS) 症状水平，及其社会心理功能和就业状况。

方法：19岁及以上（平均年龄=49.7岁，SD=13.8岁，59.8%为女性）的丧亲父母 ($n=88$) 和兄弟姐妹 ($n=34$) 完成复杂性哀伤量表 (ICG)、事件影响量表修订版 (IES-R) 和工作与社会适应量表 (WSAS) 分别用于评估 PG、PTS 和功能受损。此外，还获得了就业状况相关信息。计算了 ICG、IES-R 和 WSAS 得分高于推荐阈值的参与者比例。考查了这些测量的父母和兄弟姐妹间差异以及性别差异。

结果：共有 62.3% 的参与者的 ICG 得分表明有延长哀伤风险，而 45.9% 的参与者的 IES 得分超过临界值。PG 和 PTS 的症状之间存在高度重叠。与男性相比，女性的 ICG 和 IES 得分显著更高。父母和兄弟姐妹在 PG 和 PTS 症状上没有差异。三分之一的人在 WSAS 上表现出严重的功能受损。大约 30% 的丧亲者不在劳动力市场，三分之一的父母在恐怖袭击后无法工作。

结论：在于特岛恐怖袭击后，许多丧亲的父母和兄弟姐妹报告了长期健康后果，包括 PG 和 PTS 症状以及功能受损。结果表明需要在恐怖袭击后对丧亲者追踪，识别需要医疗服务的家庭成员。

1. Introduction

On the 22nd of July 2011, a terrorist detonated a 950 kg car bomb outside a Norwegian government building, killing 8 people. Afterwards, the terrorist travelled to the island of Utøya, where more than 500 youths were attending the summer camp organised the Norwegian Labour Party. In the span of an hour and a half, 69 people were killed and 56 people were physically injured, most of the victims were children and adolescents. This act of terror impacted the entire nation, and hundreds of people were bereaved (Dyregrov et al., 2015; NOU, 2012, pp. 14, 34).

Terrorism has a widespread impact on societies and individuals, as well as on social, economic, mental, and physical health (Cozza et al., 2019; Stene et al., 2016). Research on bereavement indicates that people generally are resilient, as they tend to adjust to loss and regain functioning over time; however, some bereaved individuals continue to struggle and develop prolonged grief (PG) (Bonanno et al., 2002; Cozza et al., 2019). The core feature of PG is a persistent and pervasive longing and preoccupation with the deceased. The bereaved may also suffer intense emotional pain, such as sadness, anger, and guilt, and experience difficulty accepting the death, as well as having a feeling of being stuck in their grief. One crucial consequence of PG is that it reduces the wellbeing and daily functioning of the bereaved individual (World Health Organisation, 2022). After non-traumatic loss, it is estimated that 10% of bereaved adults experience prolonged grief symptoms (PGS) (Lundorff et al., 2017). In contrast, approximately 49% experience PG

symptoms following a traumatic loss due to, for example, murder, suicide, disasters, or terrorism (Djelantik et al., 2020). The risk of developing PG increases owing to range of different factors, such as old age, neuroticism, female gender, insecure attachment style, past experience with mental illness, circumstances of the loss, and close relationship with the deceased (Burke & Neimeyer, 2013; Heeke et al., 2019).

A sudden and violent death caused by terrorism increases the likelihood of developing a co-occurrence of PG and symptoms of post-traumatic stress (PTS) (Djelantik et al., 2020; Dyregrov et al., 2015). In the 2014 Utøya study, conducted 18-months post loss, 81% of the parents and 75% of the sibling's reported PG symptoms and scored above the cut off >25 on the Inventory of complicated grief. Also, 61% of the parents and 72% of the siblings' reported symptoms of post-traumatic stress on the Impact of event scale – Revised (scores fell above the cut off >34; Dyregrov et al., 2015).

Symptoms of PTS include reliving the trauma (e.g. intrusive thoughts, flashbacks, nightmares), avoidance, and manifestation of physical stress (e.g. bodily activation, hypervigilance, sleep disturbance) (World Health Organisation, 2022). Interpersonal violence and traumatic loss of a loved one are associated with developing symptoms of post-traumatic stress (Kessler et al., 2017; Olf et al., 2019). Research suggests that post-traumatic stress disorder (PTSD) following a loss may interfere with the grief process and delay recovery (Glad et al., 2022; Nakajima et al., 2012; Neria & Litz, 2004). Conversely, other studies suggested that higher PG symptoms had greater

impact on PTSD symptoms, rather than vice versa (Djelantik et al., 2018; Lenferink et al., 2020; O'Connor et al., 2015).

The violent death of a child has been associated with negative parental outcomes, intense suffering, and longer time for adjustment than after natural losses of adults (Cozza et al., 2019; Séguin et al., 1995). Studies have documented high levels of prolonged grief disorder (PGD) even several decades after a traumatic loss (Pivar & Field, 2004; Schaal et al., 2010; Stammel et al., 2013). Bereavement following the traumatic loss of a child is related to functional impairment and poor physical and mental health (Cozza et al., 2019). For instance, parents who lost their child due to suicide or an accident are at a higher risk of work-related functional impairments, hospitalisation, and work absence due to mental health issues (Wilcox et al., 2015). Bereaved parents can experience secondary traumatisation when confronted with the justice system, media, or insensitive employers, and report an inability to manage work responsibilities (Rando, 1996). Research also found that five years after the death of a child, many fathers (13%) and mothers (28%) still met the criteria for PTSD (Murphy et al., 2003). Severe grief reactions and PTSD comorbidity is associated with greater work and social impairment (Simon et al., 2007).

Siblings' grief and need for support has generally been less socially recognised and therefore somewhat neglected in research (Bauwens, 2017; Viglione, 2013). The sparse existing literature indicates that siblings are affected by the tension and changes that the loss evokes in the family (Bolton et al., 2016; Schwab, 1997). For instance, one study showed that bereaved siblings can experience secondary losses, such as loss of support from parents and other siblings that are no longer able to support them (Bauwens, 2017). Another study found that siblings who lost a sibling due to murder had significant levels of PTSD, functional impairment, and many unmet needs five months after the loss (Freeman et al., 1996). Taken together, the loss of a sibling following a terror attack can have considerable negative impact on the everyday functioning and mental health of the surviving sibling (Dyregrov et al., 2015). Unfortunately, there is currently a lack of systematic research concerning the long-term effects of losing a sibling due to terrorism (Bauwens, 2017). There is a need for better understanding of the long-term consequences of traumatic death among parents and siblings after terrorism (Djelantik et al., 2020; Heeke et al., 2019; Wilcox et al., 2015).

Accordingly, the overall aim of this study was to investigate the levels of symptoms of prolonged grief, trauma reactions, and functioning of bereaved family members among participants using a survey eight years after the Utøya terror attack. The study

set out to investigate the following three specific aims: (1) the prevalence of prolonged grief (PG) and post-traumatic stress (PTS) symptoms among the parents and siblings of the Utøya terrorist attack victims, as well as gender differences eight years later (aim 1), (2) the relationship between PG and PTS symptoms in the bereaved parents and siblings (aim 2), and (3) the level of functioning and employment status of the bereaved parents and siblings as well as gender differences, and the relationship of functional impairment with PG and PTS symptoms (aim 3).

2. Methods

This study is a part of a comprehensive longitudinal project, 'Bereaved after Utøya Terror Attack 22 July 2011', at the Center for Crisis Psychology at the University of Bergen in Norway. The project aims to increase knowledge about the situations of bereaved parents, siblings, and friends after the Utøya terror attack (Dyregrov et al., 2015). Data was collected 18 months (T1), 28 months (T2), 40 months (T3), and 96 months (T4) after the terror attack. Public records of the deceased were linked to the National Population Register (NPR) to obtain the names of the parents and siblings. Only Norwegian citizens were included in the study. Two deceased individuals were not Norwegian citizens and not registered in the NPR, and one deceased had no living parents, so they were excluded from the study. Family members who were on Utøya during the attack were invited to participate in a project on survivors' mental health and were therefore excluded from the study on the bereaved after the attack.

At T4, the parents and siblings received an information sheet by post about the study, along with an invitation to participate. Prospective participants were able to provide their informed consent by mail. Participants who consented to participate in the study could then choose to complete the questionnaire by mail or through the digital questionnaire platform Survey Monkey. Participation was voluntary and involvement was not compensated. The participants could withdraw at any time.

The present study is a cross-sectional study focusing on the parents and siblings and based on the fourth data collection eight years after the terror attack (T4).

2.1. Measures

The questionnaire administered at T4 included questions regarding symptoms of PG and PTS, and functional impairment, which were used in the present investigation. Demographic information included gender, marital status, level of education and employment status.

2.1.1. Prolonged grief

To assess PG symptoms, the Inventory of Complicated Grief (ICG; Prigerson et al., 1995) was utilised. The ICG is widely used to assess the severity of clinical impairing grief (e.g. Cozza et al., 2019). The ICG is a 19-item self-report inventory that assesses the frequency of grief symptoms in the past two weeks on a 5-point scale from 0 (never) to 4 (always). The total score can range from 0 to 76. A cut-off of 25 is recommended for probable PG (Prigerson et al., 1995). The ICG has proved internal consistency, criteria, and convergent validity. The ICG has recently been validated in Norwegian (Thimm et al., 2019). In the present sample, Cronbach's alpha was .91.

2.1.2. Post-traumatic stress

The Impact of Event Scale-Revised (IES-R; Horowitz et al., 1979; Weiss, 2007) is a 22-item self-report measure that assesses symptoms of PTS (avoidance, intrusion, and hyperarousal) after traumatic events. Answers are rated on a 5-point scale ranging from 0 (not at all) to 4 (extremely). The total score can range from 0 to 88. Scores above 33 are considered high (Creamer et al., 2003). The Norwegian IES-R has shown good psychometric properties in a non-clinical sample (Eid et al., 2009). In the present sample, Cronbach's alpha was .94.

Functional impairment: The Work and Social Adjustment Scale (WSAS) is a 5-item self-report measure of functional impairment attributable to an identified disorder or problem (Mundt et al., 2002). The WSAS is widely used and is seen as a reliable measure for assessing abilities in work and social functioning. The response options are rated on a nine-point Likert scale, from 0 (not at all) to 8 (severely impaired). The sum score can range from 0 to 40. The WSAS has shown adequate psychometric properties (Mataix-Cols et al., 2005; Mundt et al., 2002) and is validated in Norwegian (Pedersen et al., 2017). According to Mundt et al. (2002), scores between 10–20 suggest significant impairment, and scores between 21 and 40 indicate moderately severe to severe functional social and work life impairment. In the present sample, Cronbach's alpha was .89.

2.1.3. Employment status

Employment status was measured with the following self-report questions: 'What was your employment status on July 22, 2011?' and 'What is your current employment status?'. The question had eight answer options: Full-time employee, part-time employee, student, unemployed, sick leave/work assessment allowance, old-age, or early retiree, incapacity to work, conscript/civilian worker. The last question was: 'If your work situation is different now compared to July 22, 2011, do you consider that these changes are related to what you experienced in connection with

the terrorist attack?'. The question had three answer options: 'yes', 'no', and 'don't know'.

2.2. Analysis

Statistical analyses were performed with SPSS version 25. We conducted descriptive analyses for the demographic characteristics. The correlation between PG symptoms of parents and PG symptoms of siblings in the same family was computed using intraclass correlation (ICC). To examine the prevalence PG and PTS symptoms, the frequencies of participants scoring above the cut offs of 25 (ICG) and 33 (IES-R) were calculated. T-tests were used to compare the means on the ICG, IES, WSAS, and employment status between the groups of parents and siblings as well as between males and females. Chi-square tests were performed to compare the prevalence of PG and PTS symptoms between parents and siblings and to compare the sex distribution between responders and non-responders. To analyse the relationship between the ICG, IES, and WSAS, Pearson correlation coefficients were calculated. A multiple regression analysis was conducted to examine the associations of PG and PTS symptoms with functional impairment when controlled for the relationship with the deceased and gender. Statistical significance was defined as $p < .05$ using two-tailed tests. There were few missing data points (ICG: 0.6%, IES: 0.5%, WSAS: 2.8%, current employment status: 2.5%). When an answer on a question of a scale was missing, the mean of the remaining scale items was imputed.

3. Results

3.1. Sample characteristics

Overall, 88 parents (40 fathers and 48 mothers) and 34 siblings (9 brothers and 25 sisters) participated at T4. The bereaved parents and siblings were aged between 19 and 76 years, with a mean age of 49.7 years ($SD = 13.8$ years). The response rate was 59%. Responders were significantly older than the non-responders that had participated in the three previous Utøya studies but not at T4 ($N = 31$, $M_{age} = 41.1$ years, $p = .003$). However, there was no statistically significant difference in sex composition between the two groups ($\chi^2(1) = 0.23$, $p = .634$). Of the 69 deceased on Utøya, 48 children (69%; 24 male and 24 females) had their family represented in the study. The mean age of the deceased in this sample was 19.9 years. The demographics concerning marital status, level of education and employment status are provided in Table 1.

3.2. Levels of prolonged grief symptoms

Table 2 shows the mean and standard deviations for the total sample and broken down for gender

Table 1. Demographic characteristics of the sample.

Variables	Total
Females <i>n</i> (%)	73 (59.8)
Marital status	
Married	67 (55.4)
Single	17 (14.0)
Separated/divorced	11 (9.1)
Cohabiting	25 (20.7)
Have boyfriend/girlfriend	1 (0.8)
Total	121
Level of education	
Elementary school	8 (6.6%)
High school	48 (39.3%)
College/University up to 4 years	38 (31.1%)
College/University over 4 years	28 (23.0)
Total	122
Mean age years (<i>SD</i> , <i>range</i>)	
Siblings	30.79 (9.57, 19-55)
Parents	57.02 (5.98, 43-76)
Employment status	
Full-time employee	64 (53.8)
Part-time employee	10 (8.4)
Student	9 (7.6)
Unemployed	1 (0.8)
Sick leave/work assessment allowance	5 (4.2)
Old age, or early retiree	3 (2.5)
Incapacity to work	21 (17.6)
Working part-time and incapacity to work	5 (4.2)
Disabled, on sick leave and working part-time	1 (0.8)
Total	119

and relationships to the deceased. The mean ICG sum score in the total sample was 30.71 ($SD = 13.13$). As shown in Table 2, parents scored on average higher than siblings on the ICG (31.76 vs 28.00), although the difference was not statistically significant ($t(120) = 1.43$, $p = .156$, $d = 0.29$). There was no correlation between the parents' and siblings' levels of grief within families ($ICC = .00$). Females scored higher than males, and this gender difference was statistically significant (33.24 vs 26.94, $t(120) = 2.67$, $p = .009$, $d = 0.49$). Results showed that 62.3% of the participants scored above recommended cut-off (>25) on the ICG: 69.9% of the females and 51.0% of the males. This difference was statistically significant ($\chi^2(1) = 4.43$, $p = .035$). The difference between parents (65.9%) and siblings (52.9%) was not statistically significant ($\chi^2(1) = 1.76$, $p = .185$).

Table 2. ICG and IES-R scores of the bereaved parents and siblings 8 years after the Utøya terror attack.

	ICG						IES					
	<i>M</i>	<i>SD</i>	<i>t</i> (<i>df</i>)	<i>p</i>	% over cutoff	<i>p</i>	<i>M</i>	<i>SD</i>	<i>t</i> (<i>df</i>)	<i>p</i>	% over cutoff	<i>p</i>
Total (<i>n</i> = 122)	30.71	13.13			62.3%		30.21	17.98			45.9%	
Gender												
Female (<i>n</i> = 73)	33.25	12.62			69.9%		33.07	17.58			52.1%	
Male (<i>n</i> = 49)	26.94	13.09	2.67 (120)	.009	51.0%	.035	25.95	17.91	2.18 (120)	.031	36.7%	.096
Relation												
Parent (<i>n</i> = 88)	31.76	13.08			65.9%		31.31	17.29			50.0%	
Sibling (<i>n</i> = 34)	28.00	13.05	1.43 (120)	.156	52.9%	.185	27.37	19.65	1.09 (120)	.280	35.3%	.144

ICG: Inventory of Complicated Grief, IES-R: Impact of Event Scale-Revised, *M*: Mean, *SD*: Standard deviation, *t*(*df*): *t* value (degrees of freedom).

3.3. Levels of post-traumatic stress symptoms

Table 2 shows the mean and standard deviations for the total sample, gender, and relationship to the deceased. The mean IES score in the total sample was 30.21 ($SD = 17.98$). The difference between parents and siblings was not significant (31.31 vs 27.37, $t(120) = 1.09$, $p = .280$, $d = 0.22$). Females scored significantly higher than males (33.07 vs 25.95, $t(120) = 2.18$, $p = .031$, $d = 0.40$). The results showed that 45.9% of all bereaved reported levels over cut-off (>33) on the IES, 52.1% of the females and 36.7% of males. This difference was not statistically significant ($\chi^2(1) = 2.77$, $p = .096$). The difference between parents (50.0%) and siblings (35.5%) was not statistically significant ($\chi^2(1) = 2.13$, $p = .144$).

3.4. Association between PG and PTS symptoms

There was a statistically significant correlation between PG and PTS symptoms ($r = .80$, $p < .001$). Of all participants, 42.6% scored above cut-off on both the IES and the ICG. Of those scoring above cut-off on the ICG, 68.4% also scored above cut-off on the IES. Of those scoring above cut-off on the IES, 92.9% also scored above cut-off on the ICG.

3.5. Functional impairment

Table 3 shows the mean and standard deviations for the total sample, gender, and relationship to the deceased. The mean WSAS score for the total sample was 15.23 ($SD = 10.27$). Of all participants, 67% scored above the cut-off >10 on the WSAS, suggesting functional impairment. The difference in the WSAS mean score between parents (15.84) and siblings (13.70) was not statistically significant ($t(116) = 1.02$, $p = .312$, $d = 0.21$). There was no significant gender difference between the males (13.30) and females (16.52) on the WSAS sum score ($t(116) = 1.68$, $p = .095$, $d = 0.32$).

Table 3. WSAS scores of the bereaved parents and siblings 8 years after the Utøya terror attack.

	WSAS						
	<i>M</i>	<i>SD</i>	<i>p</i>	Score < 10	Score 10–20 (%)	Score > 20 (%)	<i>p</i>
Total	15.23	10.27		33.1%	33.9%	33.1%	
Gender							
Female (<i>n</i> = 71)	16.52	9.89		28.2%	33.8%	38.0%	
Male (<i>n</i> = 47)	13.30	10.63	.095	40.4%	34.0%	25.5%	.270
Relation							
Parent (<i>n</i> = 85)	15.84	9.84		29.4%	37.6%	32.9%	
Sibling (<i>n</i> = 33)	13.70	11.33	.312	42.4%	24.2%	33.3%	.290

M: Mean, *SD*: Standard deviation, *p*: *p* value.

3.6. Associations of PG and PTS symptoms with functional impairment

To investigate the relationship between PTS and PG with functional impairment, correlational analyses were run. There was a statistically significant correlation of the WSAS sum score with the ICG sum score ($r = .47$, $p < .001$) and the IES sum score ($r = .56$, $p < .001$). The results show that higher levels of PG and PTS symptoms were both significantly and positively associated with functional impairment. Results of the regression analysis showed that the ICG, the IES, the relationship with the deceased, and gender explained 28.9% of the variance in WSAS scores ($F(4, 113) = 12.91$, $p < .001$). The IES sum score was a significant individual predictor ($\beta = .49$, $p < .001$) in contrast to the ICG sum score ($\beta = .06$, $p = .632$), the relationship with the deceased ($\beta = -.04$, $p = .624$), and gender ($\beta = .05$, $p = .578$).

3.7. Employment status

As displayed in Table 1, 69.7% ($n = 83$) of the bereaved participants had an active employment status (working full-time, part-time, or being a student) without receiving disability pension (versus 91% before the attack). Of the parents, 30.3% received disability pension compared to 6.8% before the terror attack. Those with an active employment status had a mean score of 28.2 on the ICG and 27.2 on the IES, respectively. Bereaved with a non-active employment status (unemployed, sick leave/work assessment allowance, old-age, or early retiree, incapacity to work) had significantly higher scores than those with an active employment status on the ICG (36.78 vs 28.18, $t(117) = 3.43$, $p = .001$, $d = 0.68$), IES (37.11 vs 27.19, $t(117) = 2.78$, $p = .005$, $d = 0.57$), and WSAS (21.88 vs 12.73, $t(114) = 4.77$, $p < .001$, $d = 0.97$). Of the bereaved, 56.4% attributed change in work status to the terror attack, 12.8 were unsure of the reason.

4. Discussion

The overall aim of the study was to explore the prevalence of bereaved parents' and siblings' prolonged

grief and post-traumatic stress symptom levels, as well as their level of functioning, in a sample of respondents eight years after the Utøya terror attack. The main findings were that approximately 60% of the parents and siblings reported symptoms of PG, and almost 50% of the parents and siblings had high levels of PTS symptoms. Many bereaved had as well impaired functioning; no significant differences between parents and siblings regarding these findings were found. Females had significant higher levels of PG, and PTS symptoms compared with males eight years after their traumatic loss by terrorism. These findings align with earlier research on traumatic losses in general and is consistent with a small number of terrorism specific bereavement studies (Cozza et al., 2019; Neria et al., 2007; Shear et al., 2006), suggesting that traumatic loss of close family members constitutes a risk factor for more intense and debilitating grief compared to non-violent losses. Furthermore, a comparison between parents' and siblings' PG and PTS symptom levels at 18-month (T1) following the Utøya attack (Dyregrov et al., 2015) and our results at 96 months (T4) showed a PG symptoms reduction of 14% for parents and 22% for siblings. The PTS symptoms were reduced by 11% for parents and 37% for siblings. These results suggest that PG and PTS symptom levels reduces over time. Moreover, Kristensen et al. (2020) reported the mean PG symptom levels on the ICG as 37.52 at 18 months (T1), 34.49 at 28 months (T2) and 32.46 at 40 months (T3) after the attack. These findings are comparable to our study ($M = 30.71$), which suggests that the level of prolonged grief remains relatively stable by 40 months.

The impact of bereavement among siblings have been studied sparsely and is less acknowledged, compared to parents' grief (Bolton et al., 2016). A commonly held assumption is that the loss of a child is a more difficult experience than losing a sibling (Doka, 2008; Rostila et al., 2012). In contrast, our findings showed no significant differences between the levels of PG and PTS symptoms between parents and siblings, suggesting that a loss after a terror attack possibly had similar impact on siblings and parents. This finding could possibly support the notion that

kinship matters to a lesser extent than previously theorised (Pivar & Field, 2004; Schaal et al., 2010). Several possible explanations have been suggested to explain why siblings' and parents' levels of grief were relatively similar. The close and long-lasting relationship that often exist between siblings is unique and can after traumatic death be followed by a strong grief, which is often unrecognised in our society (Bolton et al., 2016). It is also possible that siblings are affected by how parents are coping (Krell & Rabkin, 1979). By contrast, however, our finding revealed that there was no correlation between parents' and siblings' grief reactions in with families. It is possible that the family dynamics changes over time, for instance, family members not living together may affect coping strategies to an extent. However, it is also possible that the non-significant finding may be due lack of statistical power as the study included relatively few siblings.

The significantly higher prevalence and intensity of PG and PTS symptoms among females in our study is in line with research literature, where female gender is suggested to be a potential risk factor for severe PG and PTS reactions (Burke & Neimeyer, 2013; Kessler et al., 2017).

Several reasons can be considered for the high levels of suffering observed. The sample consists only of close family members who lost their loved ones in the same violent and traumatic event. Additionally, the circumstances of the death are crucial since the terror attack on Utøya was a targeted and planned massacre of children and youths. Finally, most of the victims were between 14 and 19 – an age particularly associated with intense parental grief (Wijngaards-de Meij et al., 2005). It is worth noting that due to the national and international media attention, Utøya can be considered a 'national trauma' with immersive impact far beyond those directly affected (Silver et al., 2004). Specifically, research shows that prolonged stressful media coverage following a terrorist attack may increase further trauma and expose bereaved individuals to trauma triggers (Pfefferbaum et al., 2018). Avoidance of triggers (such as tabloid media) that remind of the terror attack may impair normal functioning and work life engagement (Kristensen et al., 2016), and are negative factors hindering recovery (Bauwens, 2017).

The findings showed that 9 out of 10 bereaved parents and siblings with severe PG symptoms also had severe PTS symptoms. This finding of high comorbidity has also been found in prior studies (Cozza et al., 2019; Kristensen et al., 2015; Neria et al., 2007; Simon et al., 2007). Research has shown that PGD comorbid with PTSD, MDD, or anxiety disorders is associated with lower quality of life and higher levels of grief symptoms as well as elevated functional impairment compared to single diagnoses

(Komischke-Konnerup et al., 2021). Schaal et al. (2010) suggested that symptoms of PTSD may hinder the mourning process. Moreover, another study has found lower remission rates in those with PTSD comorbid with PGD than those with one condition (Simon et al., 2020).

Approximately 2 out of 3 participants (67%) reported severe functional impairments which were associated with moderate to severe psychopathology. Furthermore, both the intensity of PG and PTS symptoms was significantly correlated with social and work impairment. These results are in line with research showing that functional impairment and high mental distress often appear after traumatic losses (Cozza et al., 2019; Heeke et al., 2019; Murphy et al., 2003). However, when PG and PTS symptoms were analysed combined, only PTS symptoms predicted significantly functional impairment, suggesting that PTS symptoms has a stronger effect on psychosocial functioning than PG symptoms among the bereaved in our sample. We did not find any significant gender differences in functional impairment. Although, some researchers have found that women to a larger extent suffer functional impairment and mental health issues after the loss of a child compared to males (Kristensen et al., 2012; Xu et al., 2013). However, most studies had shorter follow-up compared to this study.

The problems related to loss are still reducing the ability of many bereaved to work. Approximately 30% of all the bereaved in this study were outside the labour market; those not working had significantly higher grief and PTS reactions. Our results showed that one third of the parents had become incapacitated to work and attributed this as a lifechanging consequence caused by the terror attack. Commonly, work constitutes a routine and continuity in life that is highly valued among bereaved. Unfortunately, PG and PTS symptoms following a traumatic loss can cause serious problems in the process of returning to work (Barlé et al., 2017).

The study's findings indicate long-term treatment needs among bereaved parents and siblings after terrorism and call for expertise among clinicians in assessment and evidence-based treatment for both PG and PTS (Simon et al., 2020). There are several evidence-based treatments targeting PG, e.g. prolonged grief disorder therapy (Shear et al., 2016), as well as for post-traumatic stress, e.g. EMDR (Solomon & Rando, 2007). Other promising treatments directed towards traumatic grief are also showing good results but need more research (Pearlman et al., 2014; Smid et al., 2015). Healthcare providers should proactively follow up bereaved after violent and potentially traumatic death, and screen for health impairments both acute and over time.

The strengths of the present study are a relatively high response rate so long after the loss and a

homogenous sample of parents and siblings who all lost a young family member under the same traumatic circumstances. Another strength is the relatively high number of male participants (40.2%), which provides a more balanced sample compared to mostly grief research on traumatic grief, where bereaved men often are underrepresented (Neria et al., 2007; Xu et al., 2013).

On the other hand, the present study has important limitations. Firstly, the ICG does not assess PGD as defined by the diagnostic criteria outlined in ICD-11 (Prigerson & Maciejewski, 2017; World Health Organisation, 2022). Secondly, the ICG appear to lack predictive validity, and has poor diagnostic specificity concerning repercussions on future health, mental disorders, and functional impairment (Maciejewski et al., 2016). Finally, the ICG has also been criticised for providing an overestimation of the frequency of prolonged grief symptoms, as it also measures normal bereavement (Prigerson & Maciejewski, 2017), and the empirical basis for setting the cut-off point as 25 on the ICG remain unclear (Thimm et al., 2019). It is possible that these factors may have contributed to the higher prevalence reported PGS in this study. Furthermore, the measurement of PG and PTS symptoms is based exclusively on self-reports by the bereaved and not through a clinical diagnostic interview. Therefore, the results may not be used as reliable evidence for the prevalence of prolonged grief disorder and post-traumatic stress disorder. Acts of terrorism also differ with respect to their settings, methods, involved risk factors, and impact, which may lead to different health consequences and can make study results hard to compare with each other. The use of different scales for assessing symptoms of PG and PTS may also contribute to diverging findings between studies. Finally, sample and recruitment bias may have led to an underestimation or overestimation of PG and PTS levels among the bereaved participants after the Utøya terror attack. The nonrespondents' levels of PG and PTS is unknown.

The participants were bereaved parents and siblings, and the interpersonal relations in the family may have influenced the symptomatology. More research is needed to better understand how interrelatedness within the family influences the individual's grief process (Heeke et al., 2019). The field of grief research would benefit from implementing direct measures of PGD that is based on the ICD-11 diagnostic criteria, as well as improved diagnostic validity, sensitivity, and accuracy to minimise the risk for pathologizing natural grief. For a better understanding of the grief process after a traumatic loss and the potential development of PGD, also a qualitative research approach would be valuable (Bauwens, 2017). In-depth interviews could provide knowledge of the phenomenology of grief and trauma processes

regarding traumatic grief after terrorism. Further, evaluative healthcare research in the aftermath of terrorism is needed to improve the healthcare system (Cozza et al., 2019; Pirard et al., 2020).

In conclusion, this long-term study eight years after the 22nd of July terrorist attack showed that the loss of a child and sibling through terrorism are comparable, as both have devastating and long-lasting consequences among the surviving parents and siblings. Many bereaved participants of this study reported high levels of PG and PTS symptoms as well as impaired social and work functioning. Therefore, healthcare staff working with bereaved individuals following acts of terrorism should be trained in assessment and treatment for PG and PTS. More attention could be given siblings grief both in the society, the health care system and within research. It would be beneficial to establish a family perspective where both parents' and siblings' grief as well as potential health consequences get recognised and acknowledged. To acknowledge siblings' grief, health care staff need to include siblings in the follow up, including those who do not live with their parents. Community outreach programs should be established for bereaved family members after traumatic death to enable early interventions and identify bereaved with more persistent needs.

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Ethics statement

Since this study involves human participants, it was reviewed and approved by the Regional Committees for Medical and Health Research Ethics in Norway (REC South-East A 210/2174). Written informed consent to engage in this study was given by all participants.

Data availability statement

Due to the sensitive data and personally identifiable information, legal restrictions prohibit the sharing of the data.


Disclosure statement

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