

Death Studies



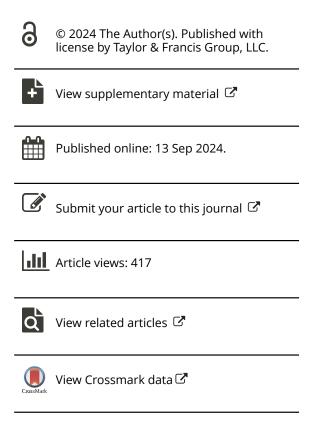
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Bereaved parents' and siblings' healthcare needs, healthcare utilization, and satisfaction with healthcare services eight years after the 2011 Utøya terror attack

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ABSTRACT

Understanding the healthcare needs of bereaved individuals following terrorism is crucial for organizing healthcare services. This cross-sectional study examined the terror-related healthcare needs, healthcare utilization, and satisfaction with professional healthcare among 122 traumatically bereaved parents and siblings eight years after the 2011 Utøya terrorist attack in Norway. Results showed that over 50% of the participants currently needed help coping with their grief or with mental and somatic symptoms, and only 34% were actively utilizing healthcare related to the terror attack. Furthermore, 68% reported not getting sufficient help, suggesting a treatment gap. One-third rated the professional help and treatment as unsatisfactory, with 28% reporting that they had not received competent help. More somatic and posttraumatic stress symptoms were associated with higher healthcare needs, whilst higher levels of insomnia symptoms were associated with lower healthcare satisfaction. This emphasizes the need to recognize, professionally intervene, and provide competent support for traumatically bereaved individuals.

KEYWORDS

Terrorism; bereavement; prolonged grief; posttraumatic stress; healthcare utilization

Terrorism is a man-made, unexpected event that is intended to inflict great harm and fear upon society and presents a significant societal challenge, with its worst consequence being the loss of lives and the infliction of traumatic bereavement on people (Cozza et al., 2019; Pearlman et al., 2014). Individuals bereaved by terrorism can experience severe psychological and somatic problems for years afterward, whether continuously or after a considerable period (Cozza et al., 2019; Kristensen et al., 2020; Nordström et al., 2024). Recovery from bereavement following violent deaths, such as those resulting from terrorist attacks, also appears to be slower than after natural deaths (Kristensen et al., 2012; Pociunaite et al., 2023). Bereaved individuals commonly report different healthcare needs (HCN) (Lenferink et al., 2021; Lichtenthal et al., 2015). HCN may arise from morbidity, pain, functional impairment, or the fear of death. These needs are directed toward resources, such as professional help, that can ideally meet them (Acheson, 1978). High levels of psychological and somatic symptoms can lead to HCN among

traumatically bereaved individuals (Fairbrother et al., 2004; Ghuman et al., 2014).

Experiencing grief and stress symptoms is a common response to traumatic bereavement (Pearlman et al., 2014); however, when these symptoms persist and do not improve over time-evolving into prolonged grief symptoms (PGS) and posttraumatic stress symptoms (PTSS)—they can lead to significant functional impairment (Cozza et al., 2019). This may manifest in difficulties with daily activities, workplace challenges, and relationship troubles. PGS are characterized by intense longing, yearning, and preoccupation with the deceased, as well as painful emotions, difficulties in accepting the reality of the loss, and avoidance of loss-related reminders (World Health Organization, 2022). PTSS are characterized by the reexperiencing of traumatic memories, avoiding trauma triggers, and experiencing bodily hyperarousal (World Health Organization, 2022). Higher levels of PGS and PTSS are more common among females (Burke et al., 2013; Kessler et al., 2017), and are associated with somatic symptoms, such as pain, hyperarousal, and

energy loss (Gupta, 2013; Stroebe et al., 2007). Somatic symptoms have received little attention in the bereavement literature but can play an important role in better understanding the long-term sequelae of terrorism (Nordström et al., 2024). Insomnia is also associated with PGS and PTSS (Lancel et al., 2020; Lewis et al., 2020). Insomnia may implicate the development of PGS and PTSS due to the role it plays in the emotional processing of negative life events, including bereavement (de Lang et al., 2023, 2024). Therefore, PGS, PTSS, somatic symptoms, and insomnia symptoms are important to include in the exploration of variables associated with HCN and healthcare satisfaction among traumatically bereaved individuals. The background for this study is the terrorist attack at the political summer youth camp on the Norwegian island of Utøya in 2011, where a terrorist killed 69 individuals, most of whom were children and teenagers (NOU 2012: 14). Eight years after the Utøya terror attack, bereaved parents and siblings reported high levels of PGS (70%), PTSS (46%), functional impairment (67%), insomnia (68%), and a variety of highly prevalent somatic symptoms, such as fatigue and pain (Nordström et al., 2024; Nordström et al., 2022). High symptom levels years after terrorist attacks may indicate elevated HCN among the traumatically bereaved. Gaining a better understanding of the symptomatology and the long-term HCN of those who are traumatically bereaved is crucial (Elhai et al., 2005; Lenferink et al., 2021).

Research on healthcare utilization following terrorism has centered on survivors, rescuers, and witnesses who may have experienced trauma (Motreff et al., 2021; Stene et al., 2016). Bereaved individuals with PGS following the 9/11 terror attack used more psychotropics and grief-focused counseling and reported a higher utilization of mental healthcare than those without PGS (Neria et al., 2007). Having PTSS and/ or being female has been shown to be strongly related to increased healthcare utilization (Elhai et al., 2005).

Among individuals with PTSS, treatment gaps and underutilization of healthcare services are documented (Jacobson et al., 2019; Nobles et al., 2016). Ten years post-9/11, many people with PTSS conveyed an unmet HCN (Ghuman et al., 2014). Different contextual barriers can hinder healthcare utilization among trauma-exposed people after terrorism, e.g., cost, availability, attitudinal, and access barriers (Ghuman et al., 2014). Seeking professional help for PTSS can be delayed for more than a decade after traumatic events (Wang et al., 2005). Therefore, studying healthcare utilization years after a traumatic bereavement is important, not just in the close aftermath of a traumatic event (Elhai et al., 2005).

The concept of a "treatment gap"—the divergence between the need for and the actual use of healthcare services—is recognized in the bereavement context (Lenferink et al., 2021; Lichtenthal et al., 2011). Bereaved individuals with PGS and a high risk for health problems are less likely to seek medical help and receive less support than those less afflicted by grief (Aoun et al., 2015; Lichtenthal et al., 2011). Whether this pattern holds for those bereaved by terrorism remains unclear.

Evaluations of the healthcare satisfaction of terror-bereaved families have been limited (Brewin et al., 2010). Nevertheless, both service users and providers have reported problems. There are examples of terror-bereaved individuals after attacks in Tunisia (2015), Belgium (2015), and France (2016), who reported that their GP lacked knowledge, provided unsuitable offers of help, or displayed unhelpful strategies toward them (Cyhlarova et al., 2020). In the aftermath of a terrorist attack, healthcare professionals have highlighted the lack of necessary training and expertise to provide psychosocial support and healthcare interventions to individuals affected by mass casualty events (Skryabina et al., 2021). More research is therefore needed to investigate how healthcare services can improve treatment for those who experience traumatic bereavement. For societies, knowledge about bereaved individuals' professional HCN, healthcare utilization, and satisfaction with healthcare after terrorism is necessary to improve and strengthen the preparedness for future terror attacks and mass causality events (Cozza et al., 2019; Neria et al., 2007; Stene et al., 2022).

When researching HCN and healthcare utilization, it is essential to describe the context of the healthcare systems. For instance, Norway has a state-funded healthcare system, where most costs are covered by the state, and nearly 99% of the population has a general practitioner (GP) who provides primary healthcare and is a gatekeeper for specialist referrals (The Norwegian Directorate of Health, 2019). After the Utøya terror attack, Norwegian authorities instructed local municipalities to provide proactive contact and individualized psychosocial follow-up adapted to the bereaved individual's need for professional help and formal support for at least one year (Norwegian Board of Health Supervision, 2011). Subsequently, four major gatherings were organized where the bereaved individuals received psychoeducation on grief and coping strategies, peer support, and group therapy sessions, and were given the opportunity to visit Utøya (Kristensen et al., 2017).

The aims of the present study, were to explore the bereaved parents' and siblings' professional healthcare needs (aim 1), healthcare utilization (aim 2), and satisfaction with healthcare (aim 3) eight years after the 2011 Utøya terror attack. An additional aim was to investigate the potential discrepancies between the reported need for and the actual utilization of healthcare services among bereaved individuals (aim 4). A further aim of the study was to explore the associations between PGS, PTSS, somatic health symptoms, and insomnia symptoms with healthcare needs and satisfaction with healthcare (aim 5). Additionally, we sought to examine gender differences related to selected aims to explore any distinct patterns or healthcare needs.

Methods

This is a quantitative cross-sectional study with data from the fourth round of data collection (T4) 96 months (eight years) after the terror attack on Utøya that is part of the longitudinal project "Bereaved individuals after the Utøya terror 22nd July 2011" (Dyregrov et al., 2015). Inclusion criteria for the present study required that participants be parents or siblings bereaved by the Utøya terror attack. Information about potential participants was obtained by linking the public records of the deceased to the National Population Register (NPR). Only Norwegian citizens were included in the study (two non-Norwegian citizens were excluded). At T4, potential participants received an information letter about the study and were asked if they wanted to participate. They could provide their informed consent via mail. Those who gave written informed consent could answer the questionnaire on the digital Survey Monkey platform or by mail. Participants were offered voluntary and uncompensated participation with the option to withdraw at any time. The Regional Committees for Medical and Health Research Ethics in Norway granted ethical approval for this study (REC South-East A 210/2174).

Measures

Sociodemographic information consisted of gender (male, female), marital status (married, cohabiting, single, separated, divorced), level of education (elementary school, high school, college, university), employment status (active employment status, non-active employment status), and kinship to the deceased (parent, sibling). Sociodemographic variables

were collected concurrently with the rest of the data during the fourth time point (T4) of data collection.

The questions assessing professional HCN since the terror attack started with the sentence, "Now we want to ask you about your need for professional help, which you believe is related to the Utøya incident." After that, the assessment was followed by four self-report questions focusing on the current HCN: 1) "Do you currently feel a need for help coping with your grief?" 2) "Do you currently feel a need for help with mental health reactions/ailments?" 3) "Do you currently feel a need for help with bodily/physical ailments?" 4) "Are you currently getting the help you need?" In all these items, the responses were rated on a five-point Likert scale, ranging from 0 (not at all) to 4 (to a large extent). Items 1, 2, and 3 from the questions related to the current HCN were aggregated to form a cumulative score, which was then utilized to represent the current HCN. Item 4 was excluded from the current HCN scale because it focuses on help needs by assessing received help rather than symptom-related needs. In this sample, Cronbach's alpha was .70 for the current HCN scale. For item 4, "Are you currently getting the help you need?" we dichotomized the answers into two groups. We combined the response options into one group called "getting the help I need" (largely, to a very large extent) and another named "not getting the help I need" (not at all, to a small extent, and to some extent).

Utilization of healthcare services was assessed using eight self-report questions. Participants were asked whether they had received help from the following professionals/healthcare services concerning their experiences linked to the events of July 22, 2011: a psychologist in public specialist services, a general practitioner (GP), a psychologist or other help from the municipality, a private clinical psychologist or psychiatrist, a psychomotor physiotherapist, a priest, a family counselor, or another form of public help. The response options for each were "yes previously," "yes currently," and "no." For the current healthcare utilization, we created a dichotomized variable divided into participants who were currently utilizing any healthcare and a group not utilizing healthcare.

Satisfaction with the healthcare system was assessed using five self-report questions: 1) "All in all, how satisfied have you been with the availability of help?" 2) "Do you think you have been treated with care?" 3) "Do you think you have received competent help?" 4) "Have you been offered help without having to ask for it yourself?" 5) "Overall, do you consider the help and treatment you have received as satisfactory?" The response options were rated on a four-point Likert scale, ranging from 0 (not at all) to 3 (largely). To facilitate the interpretation of healthcare satisfaction, we employed a process of dichotomizing the responses into two distinct groups. The first group encompassed dissatisfaction (not at all and to a small extent), and the second group represented satisfaction (to some extent and largely). A sum score from all five questions was also used as a scale to measure healthcare satisfaction. The response option "not relevant" was re-coded as a missing value. Cronbach's alpha was .90 for the healthcare satisfaction scale.

Prolonged grief symptoms (PGS) were assessed using the Inventory of Complicated Grief (ICG) (Prigerson et al., 1995). Participants were instructed to answer questions in reference to the person they lost on Utøya. The ICG has 19 questions with answers ranging on a five-point Likert scale from 0 (never) to 4 (always). Accordingly, the total score spans 0 to 76. A cutoff of 25 was applied to indicate elevated symptoms of prolonged grief (Prigerson et al., 1995). The ICG has been validated in the Norwegian language and demonstrated internal, criteria, and convergent validity (Thimm et al., 2019). Cronbach's alpha was .91.

Posttraumatic stress symptoms (PTSS) were assessed using the self-report version of the Impact of Event Scale-Revised (IES-R) (Weiss, 2007). The IES-R has 22 questions assessing subdimensions of intrusion, avoidance, and arousal symptoms, with answers ranging on a five-point Likert scale from 0 (not at all) to 4 (extremely). The total score ranges from 0 to 88, with a score of 33 or above considered indicative of probable PTSD. The IES-R has demonstrated excellent psychometric properties in a Norwegian context (Eid et al., 2009). Cronbach's alpha was .94.

Somatic symptoms were measured by a modified Children's Somatic Symptoms Inventory (CSSI-8) (Walker & Garber, 2018). This questionnaire assesses somatic distress and nonspecific somatic symptoms in the past two weeks. The fifth question, regarding "pain in shoulder and arms," was adjusted to "other pain conditions." Three items were added: "fatigue/ lack of energy," "body pain," and "chest pain." Five items focused on pain (body pain, abdominal, head, lumbar, and other pain conditions), and six focused on other somatic symptoms (fatigue, faintness, palpitations, nausea, and weakness/powerlessness). Responses were scored on a five-point Likert scale, ranging from 0 (not at all) to 4 (a high degree). The total score ranges from 0 to 44. In the first years of the Utøya study, many participants were children and adolescents, including siblings and friends of the

deceased. Given this age diversity, the CSSI-8 instrument demonstrated usability as it is able to capture somatic symptoms in individuals from childhood through to adulthood. Similar adaptations of the CSSI-8 scale have been employed in other terrorism studies in Norway for a broad age (Bugge et al., 2017; Nordström et al., 2024; Stensland et al., 2020). Cronbach's alpha was .90.

Insomnia symptoms were measured by the Bergen Insomnia Scale (BIS) self-report (Pallesen et al., 2008). The BIS has six questions, in accordance with the diagnostic criteria for insomnia disorder (APA, 1994). Participants were asked how many days per week they had experienced each criterion in the past month. Overall, four questions assess criterion A (delayed sleep onset, difficulties maintaining sleep, early morning awakening, and non-restorative sleep), and two questions assess criterion B (daytime sleepiness/ impairment and satisfaction with sleep). The total score ranges from 0 to 42. Insomnia is indicated if at least one symptom from criterion A was reported at least three times per week along with at least one of the symptoms for criterion B. The BIS was validated in Norwegian (Pallesen et al., 2008). Cronbach's alpha was .88.

Statistical analyses

All analyses were conducted using SPSS statistics version 28. We employed a descriptive analysis to examine demographic characteristics and the prevalence of HCN (aim 1), healthcare utilization (aim 2), and satisfaction with healthcare (aim 3). Independent t-tests were used to compare the mean levels of HCN and satisfaction of healthcare between parents and siblings and between males and females. We conducted chi-square tests to examine the association between the need for healthcare and healthcare utilization, and to find out how many participants needed help but did not receive it (aim 4). To investigate the associations of PGS, PTSS, somatic symptoms, and insomnia symptoms (independent variables) with HCN and satisfaction with received healthcare (dependent variables) (aim 5), we first examined cluster effects related to family affiliation in the sample using the health need scale and healthcare satisfaction scale. Intra-class correlation coefficients (ICC) were computed, revealing no between-cluster effects among parents and siblings on the HCN scale. This suggests that the variance was primarily within individuals rather than between family clusters. As a result, we employed linear regression analyses for the HCN scale. Due to a clustering effect for family affiliation in the

healthcare satisfaction scale (ICC = .52), we employed a linear mixed-effects model. All regression models included the simultaneous entry of regressors (insomnia symptoms, somatic symptoms, PGS, and PTSS) and controlled for age, gender, and kinship to the deceased. Assumptions for the regression analyses related to linearity, homoscedasticity, collinearity, normal distribution, and variation in residuals were tested and met. Statistical significance was set at p < .05 for two-tailed tests. The dataset had few missing values (ICG 0.56%, IES-R 0.45%, CSSI-8 0.0%, BIS 1.6%). Missing responses were imputed using the mean of the remaining scale items.

Results

The sociodemographic characteristics and psychological and somatic symptom levels are presented in Table 1. Of 208 bereaved siblings and parents, 122 participated in T4 (59%), comprising 34 siblings (25 sisters and nine brothers) and 88 parents (48 mothers and 40 fathers), with a mean age of 49.7 years (SD = 13.8 years, range 19 to 76 years). Most of the bereaved participants were parents of the deceased (72%), females (60%), married or cohabiting (77%),

Table 1. Sociodemographic characteristics and psychological outcomes of the sample.

	Total
Variables	n (%)
Females n (%)	73 (59.8)
Marital status	73 (39.6)
	02 (76 0)
Married/Cohabiting	93 (76.9)
Single	17 (14.0)
Separated/Divorced	11 (9.1)
Total	121
Level of education	/>
Elementary school/High school	56 (45.9)
College/University	66 (54.1)
Total	122
Kinship	
Parent	88 (72.1)
Sibling	34 (27.9)
Mean age years (SD, range)	
Sibling	30.79 (9.57, 19-55)
Parent	57.02 (5.98, 43-76)
Employment status	
Active employment status	83 (69.8)
Non-active employment status	36 (30.1)
Total	119
Levels of prolonged grief symptoms	62.3% ($n = 76$, $M = 30.71$,
above ICG cutoff >25	SD = 13.13)
Levels of posttraumatic stress	45.9% ($n = 56$, $M = 30.21$,
symptoms above IES-R	SD = 17.98)
cutoff >33	
Levels of somatic symptoms on the	(M=11.14, SD=6.44)
modified CSSI-8	, ,
Insomnia (total BIS insomnia	68.3% ($n = 82$, $M = 18.40$,
symptoms)	SD = 11.57)
/ 1 ' '/	/-

Note: M: Mean, SD: Standard deviation. BIS: Bergen Insomnia Scale. CSSI-8: Children's Somatic Symptoms Inventory. ICG: Inventory of Complicated Grief. IES-R: Impact of Event Scale - Revised.

and had an active employment status (70%). Approximately half of them had a college or university education. A total of 48 of the 69 killed youths had relatives participating in the study. In this sample, the mean age of the deceased was 19.9 years (SD = 4.96).

Table 2 shows the current HCN of the bereaved individuals related to the terror attack (aim 1). Over half of the bereaved participants reported that they currently felt a need for help in coping with their grief (51%), mental health reactions/ailments (53%), or bodily/physical ailments (51%). Moreover, parents reported significantly greater HCN related to bodily/ physical ailments than siblings (p = .018). Overall, 73 of the bereaved individuals (68%) reported not receiving the help they currently needed, with responses ranging from "not at all" to "some extent," and there were no significant differences regarding kinship or gender. No significant difference in the total HCN score was found regarding parents' and siblings' current HCN. However, females reported a statistically significant greater need for all kinds of help compared to males; this included the total HCN score (Table S1 in the supplementary materials).

The results regarding the utilization of healthcare services (aim 2) are displayed in Table 3. Of the bereaved individuals, 93% reported having previously used public healthcare services due to the terror attack (85% siblings vs. 95% parents, $\chi^2 = 3.71$, p = .054). In total, 65% had previously used psychologists in public specialist services, and 55% used psychologists in the municipalities, which were the most previously used healthcare service providers.

Eight years after the loss, 34% were currently utilizing public healthcare services related to the terrorist attack (21% of siblings vs. 39% of parents, $\chi^2 = 3.58$, p = .058). General practitioners were the most currently used, followed by psychologists and psychomotor physiotherapists.

Regarding aim 3 (satisfaction with healthcare), a majority were satisfied with the availability of help (69%), felt they had been treated with care (85%), received competent help (70%), or found that help and treatment had been satisfactory (67%). However, the majority had not been proactively offered help without having to ask for it (66%). The independent student t-tests revealed no statistically significant difference in levels of healthcare satisfaction between parents and siblings, as displayed in Table 4. Similarly, their experiences with professional healthcare and their average scores on the satisfaction scale were comparable. No statistically significant differences were observed between parents and siblings concerning their experiences with healthcare and the average

Table 2. Prevalence of current healthcare needs and t-test comparisons between parents and siblings bereaved by the 2011 Utøya terrorist attack

							Total		Total	al	Parents	nts	Siblings	ıgs				
	Not at all n (%)	To a small extent n (%)	To some extent n (%)	Largely n (%)	To a very large extent n (%)	Not relevant n (%)	n > cutoff %	%	Ø	SD	Z	SD	M SD M SD t df p	SD	t,	df	d	P
Do you currently feel a need for help coping with your grief?	19 (15.6)	41 (33.6)	42 (34.4)	13 (10.7)	7 (5.7)		62	50.8	1.57	1.06	1.52	1.02	50.8 1.57 1.06 1.52 1.02 1.71 1.17 -0.86 120 0.394	1.17	-0.86	120	0.394	-0.17
 Do you currently feel a need for help with mental health reactions/ ailments? 	26 (21.3)	31 (25.4)	38 (31.1)	17 (13.9)	10 (8.2)		9	53.3	1.62	1.20	1.52	1.14	1.62 1.20 1.52 1.14 1.88		1.32 -1.49 120 0.139	120	0.139	-0.30
 Do you currently feel a need for help with bodily/physical ailments? 	31 (25.4)	29 (23.8)	30 (24.6)	19 (15.6)	13 (10.7)		62	50.8	1.62	1.31	1.80	1.28	1.18	1.29	2.39	120	0.018	-0.48
Are you currently getting the help you need?	24 (19.7)	19 (15.6)	30 (24.6)	24 (19.7)	11 (9.0)	14 (11.5)	35	32.4		2.19 1.29	2.13	1.22	2.38	1.47	06:0-	106 0.371	0.371	-0.20
Total healthcare needs score											1.61	0.95	0.95 1.59	1.03	0.13	120 0.897	0.897	-0.03
Notes: N = 122, M: Mean, SD: Standard Deviation, t: t value, df. degrees	Standard Dev	viation, t: t va	lue, df. degre		of freedom, p: the probability value, d: Cohen's d. Cutoff: > (To some extent)	bility value,	d: Cohen's	d. Cutof	f: > (To	some e	ktent).							

Table 3. Bereaved parents' and siblings' utilization of healthcare services linked to the Utøya terror attack 2011.

Utilization of healthcare services	Previously used	Currently used	Not used
	n (%)	n (%)	n (%)
Psychologist in public specialist service	77 (65.3)	9 (7.6)	38 (32.2)
General practitioner (GP)	70 (59.9)	29 (24.8)	32 (27.4)
Psychologist or other help from the municipality	65 (54.7)	9 (7.6)	47 (39.8)
Private clinical psychologist or psychiatrist	27 (23.7)	5 (4.4)	84 (73.7)
Psychomotor physiotherapist	13 (11.5)	7 (6.2)	94 (83.2)
Priest	45 (38.5)	0 (0.0)	72 (61.5)
Family counseling	21 (18.6)	0 (0.0)	92 (81.4)
Other public help	16 (21.3)	3 (4.0)	56 (74.7)

*Percentage of previously and not used healthcare utilization that does not add up to a hundred is due to missing data.

score for the satisfaction scale (Table 4). The average satisfaction score for females was 1.94 (SD = 0.90), whilst for males, it was 1.86 (SD = 0.76), with no statistically significant differences between their evaluation of satisfaction with the received healthcare (t(117)= 0.50, p = .616, d = 0.09).

The results for aim 4 reveal that, of the 65 participants (60%) who reported a need for help, 29 (45%) currently utilized healthcare services. Of those who expressed no current need for help with mental health reactions/ailments due to the Utøya attack, 26% had utilized healthcare services because of it.

Table 5 presents the results from the linear regression analyses exploring the associations with current HCN (aim 5). Somatic symptoms ($\beta = 0.33$, p < .001), PTSS ($\beta = 0.29$, p = .018), and age ($\beta = -0.34$, p =.012) showed statistically significant associations with the perception of a current need for help. This model explained 51% of the variance in current HCN (R^2 = .51, Adjusted $R^2 = .48$, F(7, 112) = 16.86, p < .001). Increasing age was inversely associated with HCN.

The results of a multilevel analysis examining the relationship between the variables PGS, PTSS, somatic symptoms, and insomnia symptoms with satisfaction with healthcare (aim 5) showed that insomnia symptoms were the only statistically significant individual variable associated with healthcare satisfaction (b = -0.09, SE B = 0.04, p = .014) (Table 5). Those with higher scores of insomnia symptoms were less satisfied with the help received.

Discussion

The study aimed to explore the HCN, healthcare utilization, and satisfaction with received healthcare

Fable 4. Satisfaction with professional healthcare among bereaved next-of-kin: T-test comparisons between parents and siblings bereaved by the Utøya terror attack 2011.

						Total	al	Parents	ints	Sibl	Siblings				
	Not at all n (%)	To a small extent To some extent n (%)	To some extent n (%)	Largely n (%)	Not relevant n (%)	M	SD	N	SD	W	SD	t	df	d	þ
1. All in all, how	8 (6.6)	27 (22.1)	42 (34.4)	42 (34.4)	3 (2.5)	1.99	0.93	2.01	96.0	1.94	0.81	0.39	117	969:	0.082
satisfied have you															
been with the															
availability of help?															
2. Do you think you	4 (3.3)	13 (10.7)	39 (32.0)	64 (52.5)	2 (1.6)	2.36	0.81	2.33	0.84	2.44	0.72	-0.65	118	.520	-0.133
have been treated															
with care?															
3. Do you think you	12 (9.9)	21 (17.4)	46 (38.0)	39 (32.2)	3 (2.5)	1.95	96.0	1.92	0.99	2.03	0.87	-0.56	116	.577	-0.117
have received															
competent help?															
4. Have you been	40 (32.8)	31 (25.4)	27 (22.1)	23 (18.9)	1 (0.8)	1.27	1.12	1.33	1.11	1.12	1.15	0.95	119	.342	-0.193
offered help without															
having to ask for it?															
5. All in all, do you	11 (9.0)	28 (23.0)	43 (35.2)	37 (30.3)	3 (2.5)	1.89	0.95	1.89	0.98	1.90	0.91	-0.08	117	.933	-0.018
think the help and/or															
treatment you have															
received has been															
satisfactory?															
The satisfaction scale								1.90	0.85	1.88	0.73	0.10	117	.918	0.022
score															

Table 5. Associations of PGS, PTSS, insomnia, and somatic symptoms with HCN and satisfaction among parents and siblings bereaved by the 2011 Utøya terrorist attack.

Cı	ırrent he	althca	re needs		Satisfact	ion with	health	care
Variable	b	SE B	β	р	Variable	b	SE B	р
Constant	2.10	0.83		.012	Constant	6.14	4.93	.216
Age	-0.02	0.01	-0.34	.012	Age	0.08	0.06	.159
Gender	0.21	0.15	0.11	.146	Gender	0.50	0.64	.436
Kinship	-0.55	0.29	-0.25	.058	Kinship	1.77	1.70	.300
BIS	-0.01	0.01	-0.10	.247	BIS	-0.09	0.04	.014
CSSI	0.03	0.01	0.33	<.001	CSSI	-0.07	0.04	.134
ICG	0.01	0.01	0.19	.110	ICG	-0.00	0.04	.999
IES-R	0.02	0.01	0.29	.018	IES-R	-0.01	0.03	.750

Notes: b = unstandardized beta, SE B = standard error for unstandardized beta, β = standardized beta, p: the probability value, BIS = Bergen Insomnia Scale, CSSI = Children Somatic Symptoms Scale, ICG = Inventory of Complicated Grief, IES-R=Impact of Event Scale-Revised. For current healthcare needs: R = .716, $R^2 = .513$, $AR^2 = .483$.

among bereaved parents and siblings after the 2011 Utøya terror attack. Eight years after the traumatic bereavement, most bereaved individuals still had HCN, and only around one-third of the participants reported receiving the help that they needed. One-third of all bereaved individuals were actively utilizing healthcare services related to the terror attack. Almost one-third reported dissatisfaction with the help they had received earlier and stated a lack of competence among professional helpers.

Almost seven in ten bereaved individuals reported not getting sufficient professional help eight years after the terror attack. A substantial number of bereaved individuals reported a need for professional help in coping with grief, as well as mental and physical health needs related to the terror attack. The perceived need for help was common, as earlier studies of bereaved individuals have suggested (Lenferink et al., 2021; Lichtenthal et al., 2015). This study found similar levels of HCN among parents and siblings, confirming that kinship does not significantly influence the need for help (Kalsås et al., 2023). Females reported significantly higher HCN for both psychological and physical ailment, and expressed a greater need for help in coping with their grief compared to males, as has been suggested by earlier research, too (Gupta, 2013; Kessler et al., 2017).

After the terror attack, 85% of the bereaved individuals had utilized the healthcare services of psychologists/psychiatrists working in specialized services, municipalities, and private clinics, whilst 60% had received healthcare services from general practitioners (GP). The utilization of healthcare services in the initial years may have been influenced by the enormous impact the terror attack had on the bereaved individuals. The high prevalence of somatic symptoms and mental health issues associated with traumatic bereavement (Elhai et al., 2005; Nordström et al., 2024) are likely to be the reason for seeking healthcare from GPs or psychologists. Healthcare utilization for mental and somatic ailments is observed across a wide range of bereavement types (Gazibara et al., 2021; Tureluren et al., 2022). Our findings add to this knowledge base by shedding light on the long-term aspects of healthcare utilization among individuals bereaved by terrorism. The status of the Utøya terrorist attack as a national trauma, along with directives from the National Directorate for Health that required municipalities to provide a broader range of healthcare services to bereaved families than is typically expected after individual traumatic events, are likely to have played a crucial role in healthcare utilization. After terror attacks such as 9/11 and the attacks on the London Underground, proactive healthcare measures, notably victim registries, have been essential for healthcare utilization by victims. Estimates indicate that, in the absence of such follow-up programs, as many as 80% of those affected might not have sought healthcare services (Petrsoric et al., 2018). Making direct comparisons between studies remains challenging due to differences in healthcare systems in different countries. Nevertheless, the significance of free and accessible healthcare services in encouraging utilization is well-documented (Petrsoric et al., 2018).

Over time, fewer bereaved individuals used healthcare services. Eight years after the terrorist attack, a third of all bereaved individuals actively used healthcare services attributed to the attack, most commonly the healthcare services provided by a GP or a psychologist/psychiatrist. The HCN and healthcare utilization several years after the attack exceed those observed among bereaved or survivors following other traumatic losses (Kaspersen et al., 2022), as shown in other terrorism studies (Jacobson et al., 2019; Stene et al., 2016; Tucker et al., 2021). In general, healthcare utilization after disasters is low compared to the HCN that are presumed (Petrsoric et al., 2018). Wang et al. (2005) noted that the first step toward seeking help can often be the most time-consuming, sometimes taking over a decade for the initial utilization of healthcare related to PTSS. In contrast, most individuals bereaved by the Utøya terrorism had engaged with healthcare services at some point, potentially facilitating later access to healthcare services. Such prior experience with healthcare might have contributed to the continued usage or re-engagement of healthcare services among the sample (Wang et al., 2005). However, among the bereaved individuals who felt a need for help, only approximately half of them were currently utilizing healthcare services. These results suggest high unmet HCN among bereaved individuals after the Utøya terror attack. Such a discrepancy between the need for healthcare and its utilization among bereaved individuals has also been observed in earlier research (Lenferink et al., 2021). Further, we cannot assume that the healthcare utilization reported by individuals equates to their HCN being met (Kung et al., 2019). Therefore, the total range of unmet HCN could be higher than what is reported. To reduce treatment gaps and unmet needs, we must address the barriers that contribute to unmet needs (Nobles et al., 2016; Wang et al., 2005), as well as provide evidence-based bereavement care to those who need it (Breen & Moullin, 2022). Examples of barriers could be that appropriate treatment options may be lacking and immediate healthcare responses are often better organized than long-term ones (Dyregrov et al., 2019). Additionally, low satisfaction with certain aspects of received healthcare may lead patients to drop out of their treatment (Lichtenthal et al., 2015). For health professionals, it is essential to know that bereaved individuals can experience pain when talking about their bereavement and grief, and may therefore be reluctant to use healthcare services, which can lead to underutilization (Lichtenthal et al., 2015; Lichtenthal et al., 2011). Psychiatry's historical lack of a diagnosis for complicated grief could result in limited treatment options for coping with bereavement-related problems. A possible way to bridge the healthcare gaps in traumatic bereavement might be to fully implement the new diagnosis of prolonged grief disorder (World Health Organization, 2022) and to enhance the knowledge and interventions among professionals and in society (Lenferink et al., 2021).

Interestingly, a significant group utilized healthcare services despite reporting having HCN to a small extent or not at all. This could suggest that healthcare is not allocated to those who need it the most. A plausible alternative explanation is that some participants did not seek additional help because they had already received adequate support. Furthermore, individuals without high levels of symptoms, and even those without apparent mental disorders, may still consume healthcare services (Wang et al., 2005).

The results regarding healthcare satisfaction showed that many respondents reported a lack of proactive healthcare following the terror attack, despite the political directives. Only four in ten bereaved individuals were offered help from public healthcare without having asked for it. Unfortunately, this aligns with what international professionals in the field of terrorist

research often state: outreach support and follow-up frequently become complicated and fail in their practical implementation (Dyregrov et al., 2019). These results expose a potential for increased proactivity toward grieving citizens. Many of the bereaved individuals reported having received competent help and having been treated with care. At the same time, however, most bereaved individuals reported an overall dissatisfaction with the help and treatment they had received. Additionally, almost one in three of all bereaved individuals felt that they had not received competent help. Healthcare staff may lack competence in treating traumatic grief, leaving some bereaved individuals treated with care but not competence, resulting in the bereaved individuals having an unmet need for help coping with their grief. This is consistent with a recent study by Cyhlarova et al. (2020), which indicated a high level of dissatisfaction among bereaved individuals and survivors regarding various aspects of healthcare services following a terror attack. For instance, the bereaved experienced that the GP lacked knowledge, gave unsuitable offers of help, or had not been helpful toward the patients (Cyhlarova et al., 2020). Healthcare staff could benefit from improving their competence regarding traumatic grief and interventions for traumatically bereaved individuals (Stancombe et al., 2022). High levels of psychological and somatic symptoms may indicate a current need for healthcare services among traumatically bereaved individuals, which is consistent with other research on terrorism survivors (Fairbrother et al., 2004; Ghuman et al., 2014). First, PTSS was found to be significantly associated with HCN, aligning with established research on survivors of terrorism (Ghuman et al., 2014). Second, more somatic symptoms following traumatic bereavement were associated with higher HCN. This could be understood through the associations of somatic symptoms with PGS and PTSS after a terror attack (Stancombe et al., 2022; Stensland et al., 2020). This aligns with findings that prolonged bodily stress associated with traumatic bereavement can lead to both somatic and psychological HCN (Mason & Duffy, 2019; Neria et al., 2007). Our findings in the present study were in the same vein.

This study demonstrated an association between higher levels of insomnia symptoms and lower healthcare satisfaction. Given the high levels of insomnia symptoms in this sample, and these being the only variable associated with healthcare satisfaction, the results suggest that the treatment did not adequately address insomnia symptoms, thereby indicating unmet HCN. Long-term insomnia symptoms have been shown to persist when not professionally treated (Morin et al., 2020). Insomnia symptoms often persist as residual symptoms even after the effective treatment of conditions such as PTSS (Cox et al., 2017). Emerging theories suggest that insomnia symptoms could hinder the integration of trauma-related autobiographical memories, thereby perpetuating the emotional load and maintaining emotional dysregulations, including strong feelings of yearning and anger (de Lang et al., 2023). Evidence indicates that treating insomnia can reduce levels of affective and stress-related disorder symptoms, although the opposite relationship has not been definitively proven (Schnurr & Lunney, 2019; Sveen et al., 2021).

There are noteworthy clinical consequences that stem from this research. More focus on interventions for insomnia symptoms is necessary, given its strong link to PTSS (Lewis et al., 2020) and PGS (de Lang et al., 2024), which is often seen after traumatic bereavement (Lancel et al., 2020; Nordström et al., 2024). Effective treatments are needed to alleviate both insomnia and psychological distress (Schnurr & Lunney, 2019; Sveen et al., 2021). For example, cognitive behavioral therapy for insomnia (CBT-I) is an effective and feasible treatment that offers long-lasting results (Sveen et al., 2021; Talbot et al., 2014), and those who complete it gain more long-term benefits than from sleep medications. However, there is a risk of dropout due to the treatment's intensity (Mitchell et al., 2012). The results of the present study imply a need for longer planning, assessment, and the provision of customized healthcare interventions suitable for bereaved parents and siblings after a traumatic bereavement (Lee et al., 2024; Pearlman et al., 2014). Personalized help tailored to the individual's specific challenges should be offered, although determining the necessary duration is challenging. Based on the long-term HCN in coping with grief, there is a demand for more grief-focused healthcare services in the aftermath of traumatic bereavement. The high need for help with somatic ailments makes an increased focus on the somatic health of the bereaved parents and siblings necessary. The results indicate the clinical importance of asking individually about HCN. This may allow for the identification of individuals—even those at a subclinical level—who may require healthcare. Providing timely interventions could prevent their problems from remaining and worsening unnecessarily. Following an act of terrorism, a disaster registry can play a vital role in long-term healthcare by facilitating outreach, providing information, and reducing barriers to service access (Allsopp et al., 2019; Petrsoric et al., 2018). Typically, follow-up interventions for bereaved individuals primarily focus on supporting children and parents. Siblings have been an underprioritized group in comparison (Gazibara et al., 2021). Our findings demonstrate that the high level of HCN and experiences with healthcare services are similar among bereaved parents and siblings after a traumatic bereavement. This underscores the importance of recognizing bereaved siblings' suffering, taking their HCN seriously, and including them in follow-up efforts. Overall, clinicians and healthcare staff must receive more education and competence to work with traumatic grief, and sufficient resources must be allocated to ensure that they have the necessary knowledge and tools to do their work.

The study's strength lies in the diverse sample characteristics, spanning various ages and kinship relations, with all participants having experienced bereavement from the same traumatic event. Based on self-assessment questionnaires, the gender-balanced sample offered comprehensive data with minimal missing responses. Limitations include the absence of clinical interviews and diagnostic measures, as providing diagnoses was beyond the scope of the study. Therefore, we advise that updated scales, which align with the latest diagnostic criteria for prolonged grief disorder and PTSD, be used in future research, if applicable (cf. Lenferink et al., 2022; Prigerson et al., 2021). This study does not inform us about the extent of healthcare services a person utilizes, nor does it identify specific healthcare services to which healthcare satisfaction is directly related. Therefore, we recommend that future research considers register-based studies for objectively analyzing frequencies of healthcare utilization. Self-selection and recall bias may have led to an under- or overestimation of HCN, healthcare utilization, and healthcare satisfaction. Additionally, non-response bias could have influenced the findings as non-respondents' experiences remain unknown. Consequently, the difference between participants and non-participants, and its impact on the results, is unclear. The limited sample size must be considered, as it limits the study's statistical power. Therefore, any non-significant results should be approached with caution. Due to the cross-sectional design, we cannot imply causality between PGS, PTSS, somatic symptoms, and insomnia symptoms with HCN or healthcare satisfaction. However, further research could benefit from including data from different time points to enable a longitudinal research design. This would allow a better understanding of these variables' temporal relationships and potential causal pathways.

To conclude, healthcare needs following acts of terrorism and traumatic bereavement are long-term. However, over time, the use of healthcare services declines, despite persistent needs. The healthcare system must provide adequate long-term outreach programs and ensure the provision of necessary healthcare services for traumatically bereaved individuals. Healthcare services should encompass interventions addressing grief, trauma, somatic symptoms, and insomnia. An essential priority is to enhance the healthcare professionals' knowledge and capability to deliver competent, evidence-based interventions focused on traumatic bereavement.

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Data availability statement

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

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