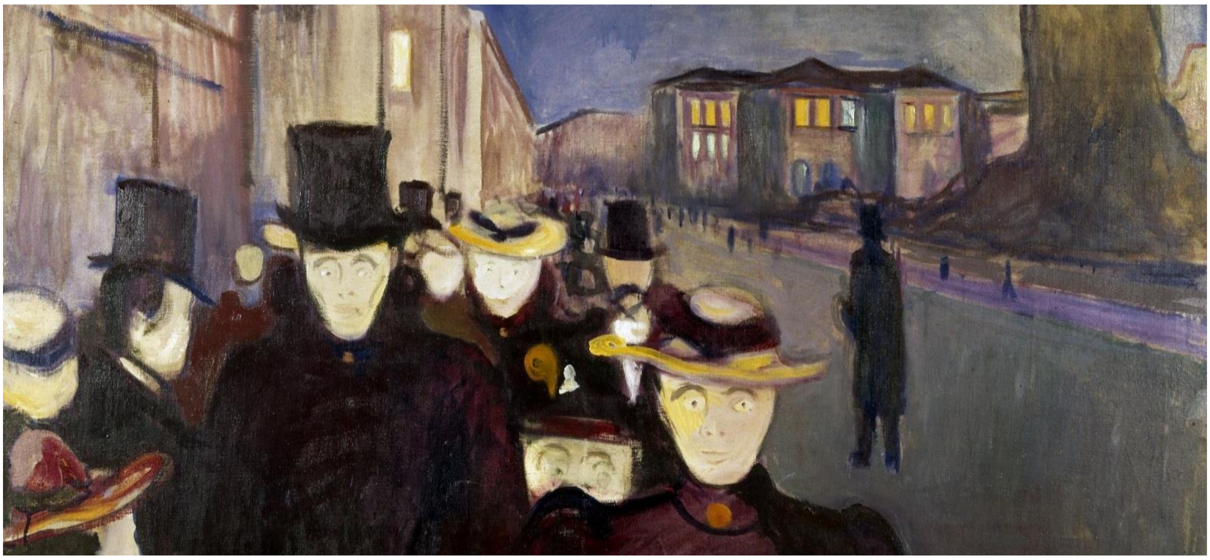
NORWEGIAN CENTRE FOR VIOLENCE
**AND TRAUMATIC STRESS STUDIES**

# Post-disaster healthcare for parents

***- a longitudinal study of the mothers and fathers of the Utøya survivors***



***Jon Magnus Haga, MD***

- Institute of Clinical Medicine,
  Faculty of Medicine, University of Oslo
- Norwegian Centre for Violence and
  Traumatic Stress Studies

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*– the truth is rarely pure and never simple*

*(Oscar Wilde)*

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## Abbreviations

| | |
|---|---|
| **APA** | American Psychiatric Association |
| **CBT** | Cognitive Behavioural Therapy |
| **CI** | Confidence interval |
| **DSM** | Diagnostic and Statistical Manual of Mental Disorders |
| **EMDR** | Eye Movement Desensitisation and Reprocessing |
| **ESTSS** | European Society for Traumatic Stress Studies |
| **GP** | General Practitioner |
| **GRADE** | Grading of Recommendations Assessment, Development and Evaluation |
| **HELFO** | Health Economics Administration Database |
| **HSCL** | Hopkins Symptom Checklist |
| **ICD** | International Classification of Diseases |
| **ICPC** | International Classification of Primary Care |
| **ISTSS** | International Society for Traumatic Stress Studies |
| **IQR** | Interquartile range |
| **N / n** | Population size / sample size |
| **NKVTS** | Norwegian Centre for Violence and Traumatic Stress Studies |
| **NPR** | Norwegian Patient Registry |
| **OR** | Odds ratio |
| **PTE** | Potentially traumatic event |
| **PTSD** | Posttraumatic Stress Disorder |
| **PTSD RI** | PTSD Reaction Index |
| **PTSR** | Posttraumatic Stress Reactions |
| **RR** | Rate ratio |
| **SD** | Standard deviation |
| **START** | National Consortium for the Study of Terrorism and Responses to Terrorism |
| **TENTS** | The European Network for Traumatic Stress |
| **UCLA** | University of California, Los Angeles |
| **WHO** | World Health Organization |

# SUMMARY

Mothers and fathers may suffer severe traumatisation from learning of or witnessing events that threaten the lives of their children. Adolescents and young adults are often among the victims of terrorist attacks, yet little is known about parents' post-disaster healthcare needs.

This thesis investigates post-disaster healthcare services provided to parents of the survivors of the 2011 Utøya terrorist attack, by combining registry-based data on parental healthcare consumption in the three-year periods before and after the terrorist attack with self-reported data from the mothers and fathers, and their children. Services addressed include regular primary and specialised healthcare and the extraordinary crisis response programme set up by municipalities throughout the country in the wake of the attack.

In brief, the extraordinary crisis response programme succeeded in reaching out to a majority of the parents. Yet, parents of non-Norwegian origin and of non-intact families ran an increased risk of being left out of the proactive follow-up. Nearly all mothers and fathers turned to their general practitioner (GP) for help, a majority for psychological health complaints. More frequent GP visits was related to higher levels of distress. A minority of the more distressed parents were additionally provided for by specialised mental healthcare providers.

In conclusion, parents witnessing or learning of a terrorist attack that threatens the life of their children may access a wide range of healthcare services, for a wide range of post-disaster health complaints. GPs may play a key role in providing for general complaints in the many, whereas specialised mental healthcare providers may play a key role in providing for the needs of the most severely traumatised.

## Paper 1

**Haga JM, Stene LE, Wentzel-Larsen T, Thoresen S, Dyb G.** Early postdisaster health outreach to modern families: a cross-sectional study. BMJ Open. 2015 Dec 17;5(12):e009402.

## Paper 2

**Haga JM, Thoresen S, Stene LE, Wentzel-Larsen T, Dyb G.** Healthcare in parents of young terrorism survivors: A registry-based study in Norway. BMJ Open. 2017 Dec 21;7(12):e018358.

## Paper 3

**Haga JM, Stene LE, Thoresen S, Wentzel-Larsen T, Dyb G.** Does posttraumatic stress predict frequency of general practitioner visits in parents of terrorism survivors? A longitudinal study. European journal of psychotraumatology. 2017 Nov 20;8(1):1389206.

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## Dissemination and research communication

For the scientific community, I have presented my work internationally in oral symposia at the 31st and 32nd annual meetings of *The International Society for Traumatic Stress Studies* (ISTSS, New Orleans, 2015 and Dallas, 2016) and the 15th Conference of *The European Society for Traumatic Stress Studies* (ESTSS, Odense, 2017) and in the poster session at the *Utøya 5-year anniversary conference* (Oslo, 2016). Additionally, I have contributed with presentations at a number of smaller events, including workshops with *The National Support Group for victims of the 22 July attacks*, *The 22nd July Research Network* and the international reference group of the Utøya study.

For the general public, I have presented my findings on national television as part of the Norwegian research communication competition *The Researchers' Grand Prix* (2015) and in the national newspaper *Aftenposten* (2015).

# INTRODUCTION

> **Personal statement:**
> *In the summer of 2008, I enjoyed my vacation at the Utøya summer camp. Three years later, I learnt that my friends on the island were in the midst of a terrorist attack. Having recently graduated from medical school, I was working in a rural hospital at the time. My commitment to the field of psychotraumatology started as a search for knowledge on how to help.*

## Overview of topic

Terrorist attacks are crimes of violence characterised by intentionality and a strong potential for provoking widespread fear (Weinberg, Pedahzur, & Hirsch-Hoefler, 2004). They may occur whenever and wherever they are least expected and inflict death, mutilation and psychological traumatisation upon their innocent victims. Those physically present at the site of the attack, as well as their close families and friends, who learn about or witness the event from afar, may develop lasting psychopathology, including posttraumatic stress disorder (PTSD), anxiety and depression (American Psychiatric Association, 1994; Whalley & Brewin, 2007).

Parents may face particular challenges in the wake of a disaster, as they may struggle to cope with their own stress reactions, and, at the same time, be expected to care for a traumatised child. Family dynamics may be disrupted. Traumatised children may become increasingly dependent on their parents, older children may move back home, and the parents may experience increased tension between themselves (Bonanno, Brewin, Kaniasty, & La Greca, 2010; Cobham, McDermott, Haslam, & Sanders, 2016).

Traditionally, research in the field of psychotraumatology has focused on the health and healthcare needs of survivors (Bonanno et al., 2010; Weisaeth, 2002). Other victims of trauma, such as close family and friends, have received less research attention. In particular, little is known about parents' health and healthcare needs in the wake of a disaster, such as a terrorist attack, which threatens the lives of their children. This thesis aims to strengthen societal preparedness to disasters by advancing current knowledge on post-disaster healthcare needs in parents of survivors.

# Key literature

Psychological ill-health following traumatic life-events has long been acknowledged. Yet, it remains a subject of considerable controversy. In the following, the historical context and current understanding of psychological trauma are outlined, followed by a brief introduction to manmade disasters, post-disaster health and post-disaster healthcare. Lastly, the notion of *'parental trauma'* is discussed.

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## ***Historical context***

Cuneiform inscriptions on Sumerian clay tablets dating from earlier than 2000 BC tell the ancient epic of *Gilgamesh*, a king struggling with intrusive recollections of a battle in which he witnessed the defeat and slaughter of his companion (Birmes, Hatton, Brunet, & Schmitt, 2003). The story is by some considered to be an early written reference to clinical distress that may have resembled PTSD. Further notable historical references to posttraumatic health complaints include the epic of the *Iliad*, traditionally attributed to Homer (~700-800 BC), featuring the hero and mythical warrior Achilles, and the history plays of William Shakespeare (1564-1616) (Birmes et al., 2003). Some argue that the health complaints of the troubled Sir Henry 'Hotspur' Percy in the Shakespeare play *King Henry IV*, such as his vivid nightmares and mood swings, would have satisfied all criteria of a modern-day PTSD diagnosis (Birmes et al., 2003).

In the medical sciences, the notion of a psychologically-induced '*trauma*' is rather novel. Reflecting suppositions of physical rather than psychological aetiology, in the 19th century, posttraumatic health complaints were known by a variety of names, such as '*spinal concussion*', '*railway spine*', '*irritable heart*', '*soldier's heart*', '*traumatic shock*', '*traumatic neurosis*', '*nervous shock*' and '*effort syndrome*' (Turnbull, 1998). Although notable pioneers in the field, including Jean-Martin Charcot (1825-1893), Pierre Marie Félix Janet (1859-1947) and Sigmund Freud (1859-1939), all suggested that posttraumatic ill-health, which they knew as '*hysteria*', and later also as '*neurasthenia*', was caused by a psychological mechanism, the leading theory well into the 20th century was that posttraumatic health complaints were connected to physical injury or organic disease, e.g. of the heart, spinal cord or the brain (Gersons & Carlier, 1992; Kinzie & Goetz, 1996; Wilson, 1994).

Posttraumatic ill-health has long been recognised as a product of horrific war experiences (McNally, 2003). In World War I, reactions to combat experiences in soldiers were known as '*shell shock*'; in World War II as '*combat fatigue*', '*war neurosis*' and '*acute exhaustion*' (Crocq & Crocq, 2000). Distress in survivors of the concentration camps was to be known as '*concentration camp syndrome*' (Eitinger, 1961), and the distress of the civilian merchant seamen as '*war sailor syndrome*' (Askevold, 1976). After World War II, precursors to the modern trauma-related diagnoses were introduced to the DSM, and later the ICD, manuals (*Table 1*). Initially, reactions were widely believed to be transient and liable to affect only the psychiatrically impaired or predisposed (Kinzie & Goetz, 1996).

**Table 1** Trauma-related diagnoses in DSM and ICD

| | | |
|---|---|---|
| DSM-I | APA (1952) | ◦ Transient situational disturbance<br>◦ Gross stress reaction |
| DSM-II | APA (1968) | ◦ Transient situational personality disturbance<br>◦ Adjustment reaction |
| DSM-III | APA (1980) | ◦ Posttraumatic stress disorder |
| DSM-III-R | APA (1987) | ◦ Posttraumatic stress disorder with *'serious threat or harm to one's children'* explicitly included as a potentially traumatic event |
| DSM-IV | APA (1994) | ◦ Acute stress disorder<br>◦ Posttraumatic stress disorder |
| DSM-5 | APA (2013) | ◦ Acute stress disorder<br>◦ Posttraumatic stress disorder<br>◦ Other specified trauma/stress or related disorder<br>- subthreshold posttraumatic stress disorder<br>- persistent complex bereavement disorder<br>- ataques de nervios and other cultural symptoms |
| ICD-6 | WHO (1948) | ◦ Acute situational maladjustment |
| ICD-8 | WHO (1968) | ◦ Transient situational disturbance |
| ICD-9 | WHO (1977) | ◦ Acute reaction to stress |
| ICD-10 | WHO (1992) | ◦ Acute stress reaction<br>◦ Posttraumatic stress disorder<br>◦ Enduring personality changes after catastrophic experience |
| ICD-11 | WHO (2018) | ◦ Disorders specifically associated with stress, including posttraumatic stress disorder, complex posttraumatic stress disorder, prolonged grief disorder, adjustment disorder, reactive attachment disorder and disinhibited social engagement disorder.<br>◦ Problems associated with harmful or traumatic events, including acute stress reaction. |

*DSM = Diagnostic and Statistical Manual of Mental Disorders. APA = American Psychiatric Association. ICD = International Statistical Classification of Diseases. WHO = World Health Organisation.*

Reflecting changes in the perception of the disease, the diagnoses and diagnostic criteria evolved with every new edition of the manual. A particularly noteworthy development was the women's liberation movement, and with it, increased attention on women's rights and women's health in the 1970s. The resemblance of health complaints in maltreated women, known by names such as *'battered women syndrome'* (Appleton, 1980) and *'rape trauma syndrome'* (Burgess & Holmstrom, 1974), and the adverse psychological reactions observed in soldiers following their combat experiences in Vietnam, led to the recognition of domestic violence and sexual assault as having a similar capacity for eliciting posttraumatic ill-health to that of war traumas. In 1980, *'posttraumatic stress disorder (PTSD)'* was first introduced in the DSM as a trauma-specific, behavioural diagnosis, covering both combat- and non-combat-related post-traumatic complaints (American Psychiatric Association, 1980).

Looking back, our understanding of posttraumatic ill-health has developed considerably over the years, in concert with societal progress, as well as with hardship and war. It seems likely that it will to continue to evolve in the future.

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## *Current perceptions of psychological trauma*

Today, a causal relationship between traumatic experiences and subsequent health complaints is generally agreed upon, in the sense that posttraumatic health complaints would not have presented were it not for the traumatic exposure (Friedman, Keane, & Resick, 2007; Gilbertson et al., 2010). The proposed psychological mechanism of injury is referred to as *'psychological traumatisation'*, whereas events with the potential for creating psychological traumatisation are referred to as *'potentially traumatic events (PTE)'* (Bonanno, 2004). In the following, qualities of the *traumatic experience* will be outlined; an overview of posttraumatic health complaints, including PTSD, is provided in a later section (*Ill-health following manmade disasters, p. 17*).

Which events should and should not qualify as a PTE is a question which has long been debated, and is still the subject of considerable controversy. The World Health Organization (WHO) has long defined PTE in broad terms as ‘an event or situation (either short or long lasting) of exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone’ (World Health Organization, 1992). The American Psychiatric Association (APA) has adopted a more descriptive definition. In the *Diagnostic and Statistical Manual of Mental Disorders (DSM) IV*, PTE was described as ‘an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others’ (American Psychiatric Association, 1994) and in the most recent version of the manual (American Psychiatric Association, 2013), a list of qualifying events was provided (*Box 1*). The events need not involve threat to self. Witnessing or learning of a situation, in which the life of a close relative or friend is under life threat, qualifies as PTE.

---

**Box 1** Events listed in DSM 5 as potentially traumatic

- exposure to:
  - *actual or threatened death*
  - *actual or threatened serious injury*
  - *actual or threatened sexual violence*

- in terms of:
  - *directly experiencing the traumatic event(s)*
  - *witnessing, in person, the event(s) as it occurred to others*
  - *learning that the traumatic event(s) occurred to a close family member or close friend - in case of actual or threatened death of a family member or friend, the event(s) must have been violent or accidental*
  - *experiencing repeated or extreme indirect exposure to aversive details of the traumatic event(s)*

*(American Psychiatric Association, 2013)*

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## *Manmade disasters*

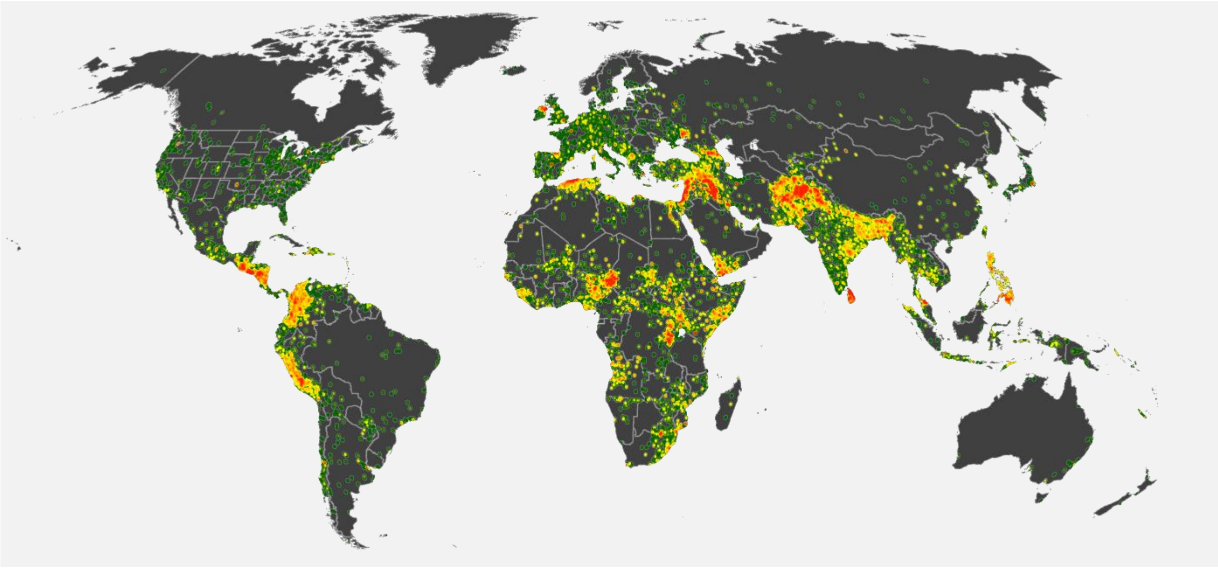
Disasters are destructive events that may cause sweeping damage, hardship, loss of lives and potentially overwhelm the resources of a society (Beach, 2010; Bonanno et al., 2010). Disasters may be natural or manmade, and expose their victims to a variety of PTEs. Unlike natural hazards, such as earthquakes, landslides, floods, storms and droughts, a '*manmade disaster*' is a destructive event that is intentionally triggered, promoted or maintained by a perpetrator or has resulted from negligence (Weinberg et al., 2004). Accidents, including industrial, mining or transportation accidents, despite pertaining to manmade structures, do not necessarily qualify as manmade disaster per this definition, due to a lack of intentionality and negligence. Thus, such incidents are often more accurately classified as '*accidents*' or '*accidental disasters*'.

'*Terrorist attack*' is a subcategory of manmade disasters, in which the perpetrator, the '*terrorist*', holds a '*terrorist intent*' (Huff & Kertzer, 2017). The term is used extensively both in academia and in the public discourse. Nonetheless, its precise definition is still much debated. The National Consortium for the Study of Terrorism and Responses to Terrorism, a US Department of Homeland Security Centre of Excellence, currently defines terrorism as 'the threatened or actual use of illegal force and violence by a non-state actor to attain a political, economic, religious, or social goal through fear, coercion or intimidation' (National Consortium for the Study of Terrorism and Responses to Terrorism (START), 2016a). According to this definition, the terrorist not only aims to harm his or her targets, but also to change public attitudes and behaviours, in line with an underlying goal.

The distinction between terrorist and non-terrorist violence is not always straightforward. Determining a motive may prove difficult, mental illness may be confused with terrorist intent and false accusations or claims of responsibility may emerge in the wake of an attack.

Globally, an increase in the number of terrorist attacks has been reported over the last decade, with a growing number of countries being affected (Institute for Economics and Peace, 2016). The deadliest year on record, 2014, saw 93 countries struck by one or more terrorist attacks, resulting in a total of 32,765 deaths. A geographical representation of the more than 150,000 terrorist attacks worldwide since 1970 is provided in *Figure 1*. Although infrequent in most countries, terrorist attacks may affect health in victims throughout the world. Relatively few terrorist attacks have been reported in Europe; despite the manifold increase observed in 2014, less than 600 fatalities were registered (Institute for Economics and Peace, 2016). Although the overall death toll represents a small proportion of mortality in Europe, terrorist attacks may still affect health and wellbeing for a much larger group, including families and friends of victims, and the general public.

**Figure 1** Terrorist attacks worldwide, 1970-2015



*Intensity colour (green=low, red=high) is a combination of fatalities and injuries. Adapted from Global Terrorism Database, GTD World Map: 45 Years of Terrorism (National Consortium for the Study of Terrorism and Responses to Terrorism (START), 2016b).*

Mass shootings represent a particular form of mass-trauma in which a perpetrator uses a firearm to harm his or her targets (Newman, Tabke, & Pfefferbaum, 2017). A number of recent mass shootings have specifically targeted adolescents and young adults at school or during their leisure time (Dyb et al., 2013; Katsiyannis, Whitford, & Ennis, 2018; Suomalainen, Haravuori, Berg, Kiviruusu, & Marttunen, 2011). Mass shootings may be ideologically motivated, and thus constitute acts of terrorism, but this is not always the case. School shootings are not generally considered terrorism, however destructive they might be, because they lack '*terrorist intent*' (Muschert, 2007). In this thesis, all mass-violence events, including terrorist attacks, will be collectively referred to as '*manmade disasters*', regardless of terrorist intent.

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## *Ill-health following manmade disasters*

Manmade disasters may induce a range of post-disaster mental and somatic health complaints, both in the early and delayed aftermath.

***Posttraumatic stress disorder (PTSD)*** is a mental disorder involving a pathological fear response to an extremely stressful stimulus, involving both a physiological stress response, by the sympathetic-adrenomedullary and hypothalamic-pituitary-adrenocortical axes, and a psychological stress response (National Collaborating Centre for Mental Health, 2005). PTSD is trauma-specific, i.e. it can only be diagnosed following exposure to a PTE.

Clinically, PTSD is defined by a set of event-related stress reactions (*Box 2*). These reactions include intrusions, avoidance and arousal, reactivity, and mood and cognition alterations (American Psychiatric Association, 1994, 2013). The detailed diagnostic criteria of PTSD have long been the source of controversy (Friedman, Resick, Bryant, & Brewin, 2011). Most prominently, harmonisation between the DSM and ICD diagnostic criteria is yet to be achieved (Bisson, 2013). Still, PTSD remains the health complaint most frequently investigated following terrorism (Whalley & Brewin, 2007). Prevalence of PTSD has been reported in the range of 10-40% in both the first and the second years following traumatic exposure to a manmade disaster, as reviewed by DiMaggio and Galea (2006), Whalley and Brewin (2007) and Paz Garcia-Vera, Sanz and Gutierrez (2016).

**Box 2** Overview DSM-IV PTSD symptom clusters (criteria B-D)

- *recurrent and intrusive distressing recollections of the event (criterion B)*
- *avoidance of stimuli and numbing of general responsiveness (criterion C)*
- *increased arousal (criterion D)*

*(American Psychiatric Association, 1994)*

The risk of suffering from PTSD is a two-level conditional risk, i.e. of experiencing a PTE and of developing PTSD following the exposure to a PTE. A majority of individuals will be '*resilient*' to the traumatic exposure, and hence will not develop severe psychopathology (Bonanno, 2004; Norris, Tracy, & Galea, 2009). Nonetheless, a minority do. Type and degree of traumatic exposure have long been recognised as important determinants of PTSD development (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). A dose-response relationship between exposure and severity of stress reactions is generally assumed, although it has been suggested that there may not be a simple linear relationship between the severity of the stressor and the incidence of PTSD (Bonanno et al., 2010). The notion of a '*ceiling effect*' has been proposed, meaning that there comes a point where increased severity of the traumatic stimuli does not produce a marginal (additional) effect.

Considerable effort has been invested in uncovering risk factors that predict the development of PTSD. In brief, '*pre-trauma factors*', such as previous trauma and family psychiatric history, '*peritraumatic factors*', such as trauma intensity, perceived life threat and emotional responses, as well as '*post-trauma factors*', such as perceived poor social support, have been shown to promote PTSD (Breslau, Troost, Bohnert, & Luo, 2013; Brewin, Andrews, & Valentine, 2000; Ozer, Best, Lipsey, & Weiss, 2003). In addition, hereditary predisposition is increasingly being acknowledged, possibly accounting for as much as one third of the total risk of developing PTSD (Banerjee, Morrison, & Ressler, 2017; Cornelis, Nugent, Amstadter, & Koenen, 2010; Logue et al., 2015). Of note, considerable heterogeneity between the studies is observed, with inconsistencies in sampling, design, measurement and statistical analyses, which may limit current conclusions.

Posttraumatic stress may also be assessed in terms of a continuous symptom score (i.e. of the number of symptoms present, the intensity of symptoms or a combination of the two). Although such scores may not be appropriate for approximating clinical diagnoses, continuous scores provide valuable information on severity of complaints and may help trace changes in stress reactions over time. Furthermore, by using a continuous scale, arbitrary cut-off points are avoided.

***Depression*** is a trauma-non-specific mental disorder characterised by deflation in mood, sleep disorder, loss of appetite, fatigue and suicidal ideation (American Psychiatric Association, 1994). Depressive reactions are common among trauma survivors, especially in the event of loss of lives, and often present as comorbidity to PTSD (Flory & Yehuda, 2015). It has been debated whether posttraumatic depressive reactions are truly distinct, in terms of a '*depression*', or whether they should be considered as by-products of a more general trauma response (Bonanno et al., 2010).

Estimated prevalence of major depressive disorder in the first year following a manmade disaster ranges between 20-30% (Salguero, Fernandez-Berrocal, Iruarrizaga, Cano-Vindel, & Galea, 2011). A lack of longitudinal studies prevents sound estimates of prevalence of depressive disorders in time periods later than one year post disaster. As with posttraumatic stress, symptoms of depression may be evaluated on continuous scales, rather than by clinical diagnosis.

***Further psychopathology*** – appearing separately or as comorbidity to PTSD – includes panic disorders, phobias, anxiety, substance abuse, suicidal ideation and traumatic grief (Bonanno et al., 2010; DiMaggio & Galea, 2006; DiMaggio, Galea, & Li, 2009; Whalley & Brewin, 2007). In particular, grief has been identified as playing an important role in post-disaster health and functioning in the bereaved (Dyregrov, Dyregrov, & Kristensen, 2015).

***Somatic health complaints*** may result from a combination of physical, psychological and social factors. The physical factors may speak to both the physical injuries sustained and to secondary, stress-induced somatic disease (Bonanno et al., 2010). Whereas physical injuries relate directly to the physical nature of the event, e.g. gunshot wounds or blast injuries, stress-related somatic health problems speak to more general mechanisms, the so-called *'allostatic load'*, the wear and tear on the body created by a lasting stress response (McEwen, 1998, 2000). Allostatic load has been shown to be associated with a range of pathological changes, including atherosclerosis, obesity, impaired immunity, brain atrophy and bone demineralisation (McEwen, 2004), as well as a respiratory, circulatory and gastrointestinal disease (Boscarino, 2004; Pacella, Hruska, & Delahanty, 2013; Schnurr, 2007).

In the particular context of manmade disasters, somatic complaints have previously been demonstrated to include cardiovascular and respiratory disease (Perlman et al., 2011), diabetes (Miller-Archie et al., 2014), low birth weight and preterm delivery (Maslow, Caramanica, Li, Stellman, & Brackbill, 2016). Furthermore, post-disaster somatic health complaints may also include medically unexplained health complaints such as medically unexplained nausea, back pain, headaches and respiratory problems (Bonanno et al., 2010). Although some researchers argue that medically unexplained somatic health complaints should be considered as a '*health cost*' of the psychological stress response, rather than being treated as a distinct entity of stress-induced somatic health complaints, it should be noted that these health complaints may be severely troublesome and disabling for those affected, regardless of biological substrate or classification.

Of note, post-disaster health problems may represent both the debut of new conditions, as well as persistence or exacerbation of pre-existing disease in the chronically ill. Thus, in order to make a detailed assessment of post-disaster health, a detailed account of pre-disaster health is required, in particular in populations where levels of pre-disaster health problems are expected to be significant, e.g. in adults and the elderly.

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## *Healthcare following manmade disasters*

The multiplicity of health hazards associated with disasters calls for a comprehensive and coordinated crisis response. Depending on the nature and magnitude of the disaster, the crisis response may draw on resources across all sectors of the society, including the public sector, with its healthcare services, social services, civil infrastructure, police and armed forces, as well as the private and the non-profit sectors (Beach, 2010). Within the crisis response framework, the overarching concept is '*preparedness*'. Preparedness encompasses precautionary measures taken on individual, familial and communal levels in order to build resilience, strengthen the capacity for predicting disaster and prepare for the delivery of timely and relevant help services of sufficient quantity and quality (Beach, 2010). Of note, healthcare providers may make a vital contribution to crisis management, both in building preparedness and in providing the necessary post-disaster healthcare services.

The organisation of healthcare services varies between countries (Kringos, Boerma, Hutchinson, & Saltman, 2015; Masseria, Irwin, Thomson, Gemmill, & Mossialos, 2009). Post-disaster roles of healthcare providers may vary accordingly, although some common key features may be pointed out. Fundamental to most Western healthcare systems is their so-called *'hierarchical structure'*. The structure is generally accredited to the British physician Bertrand Dawson (1864-1945), and the *Dawson report*, prepared for the United Kingdom Council on Medical and Administrative Services in 1920. The report distinguished between *'general'* and more *'specialised'* healthcare services and advocated for general healthcare to be provided in *'primary health centres'* and more specialised services in *'secondary health centres'* and *'teaching hospitals'* (Frenk, 2009). The notion of this hierarchical healthcare structure rapidly disseminated across Europe. In the USA, however, the structure was not embraced until well into the 1960s, when growing concern about the overemphasis on specialisation and a lack of general healthcare services sparked public debate about priorities of the healthcare system (Phillips & Bazemore, 2010), and a number of critical reports, including the *Millis Commission Report* (1966) prepared for the American Medical Association, successfully advocated for the need of every individual to have a *'primary physician'* (Phillips & Bazemore, 2010; Stevens, 2001).

In 1978, WHO put primary healthcare on the global agenda with the *Alma-Ata Declaration*, endorsing primary healthcare as a vital component in achieving *'health for all'* (World Health Organization, 1978). The declaration sought to bridge the gap between *'individual-oriented'* and *'population-based'* approaches to health, advocating for the scope of primary healthcare to be extended to include public health work (Walley et al., 2008). Today, most Western healthcare systems consist of a primary healthcare sector, incorporating public health work to a variable degree, in addition to a specialised healthcare sector (Paris, Devaux, & Wei, 2010).

***Primary healthcare*** is the entry-point to most Western healthcare systems and the principal provider of general healthcare services for a wide range of somatic, mental and social health complaints (Pedersen, Andersen, & Sondergaard, 2012; Ringard, Sagan, Sperre Saunes, & Lindahl, 2013). Primary healthcare encompasses a variety of healthcare professionals, e.g. physicians, nurses, physiotherapists and physician assistants, responsible for a wide range of services, including general diagnostics and treatments, psychosocial support, assistance in filing for social services or welfare benefits, coordination with or referrals to other help providers and so forth. In many countries, physicians within the primary healthcare services function as '*gatekeepers*' to the specialised healthcare services, as presented in *Table 2*.

**Table 2** The role of GPs as gatekeepers to the specialised healthcare services

| | | *Are GP referrals required to access specialised healthcare?* | | |
|---|---|---|---|---|
| | | *Required* | *Incentives* | *Not required, no incentives* |
| *Are people required to register with a GP?* | *Required* | Denmark<br>Finland<br>Ireland*<br>Italy<br>Netherlands<br>Portugal<br>Slovenia<br>Spain | | Czech Republic |
| | *Incentives* | Australia<br>New Zealand<br>Norway<br>Poland | Belgium<br>France<br>Switzerland | |
| | *Not required, no incentives* | Canada<br>Chile<br>United Kingdom | Mexico | Austria<br>Germany<br>Iceland<br>Israel<br>Japan<br>Korea |

** does not apply to all citizens*

*(Adapted from Paris et al., 2010)*

In healthcare systems where the GP functions as a gatekeeper, the principle of *'lowest effective level of care'* has been proposed as a guide to resource-efficient practices (Vuori, 1982). According to this principle, health problems should be solved at the lowest possible level in the healthcare hierarchy. That is, all conditions that may be handled in the primary healthcare setting are to be handled in the primary healthcare setting, without referrals to specialised healthcare services. In the Scandinavian healthcare systems this principle has been particularly influential (Christiansen, 2008; Nylenna & Larsen, 2005).

Key terminology in use in primary healthcare research needs clarification. It is generally agreed that the term *'primary care'* ought to be distinguished from the term *'primary healthcare'*. Nonetheless, their precise definitions have not been agreed upon, and the two terms are often confused (Muldoon, Hogg, & Levitt, 2006). The term *'primary healthcare'* is derived from the aforementioned *Alma-Ata Declaration*. In broad terms, it denotes multidisciplinary health work that integrates individual-oriented healthcare services with population-based public health work (Muldoon et al., 2006). *'Primary care'*, on the other hand, is a more restrictive term denoting the day-to-day, person-oriented services provided by physicians working in primary healthcare. In this thesis I have chosen to refer to the range of services administered by primary healthcare providers as *'primary healthcare services'* in order to highlight the fact that post-disaster primary healthcare may include more than what would normally fall under the definition of *'primary care'*, such as participation in the overall crisis response, coordination with other help services, with social services, schools, workplaces and so forth.

***Specialised healthcare*** refers to healthcare services provided by specially trained physicians or psychologists for a variety of health complaints that are not suitable for treatment in primary healthcare. Specialised healthcare is typically provided on a referral basis, in a hospital setting or in outpatient clinics (Paris et al., 2010). In the following, trauma-specific specialised mental healthcare interventions for adults will be outlined. Nonetheless, it is important to keep in mind that healthcare for general health complaints and for trauma-non-specific health complaints, including somatic healthcare needs, may be just as pressing, in a post-disaster context.

'*Psychotherapy*' is specialised clinical interventions that employ a psychological, rather than a biological, therapeutic approach. Although more than 70 randomised controlled trials have been conducted on psychological therapy for PTSD, in a recent Cochrane meta-analysis the evidence-base was rated as '*very low quality*' (Bisson, Roberts, Andrew, Cooper, & Lewis, 2013), according to the *Grading of recommendations assessment, development and evaluation (GRADE)* score (Andrews et al., 2013). In a majority of the studies the risk of bias was considered '*high*' or '*unclear*', largely due to '*performance bias*' (inadequate blinding of participants and personnel), '*selection bias*' (no or insufficient random sequence generation and allocation concealment) and '*attrition bias*' (loss of follow-up) (Bisson et al., 2013). Despite these notable weaknesses, current evidence on psychological interventions suggests that, when measured directly after the intervention, trauma-focused cognitive behavioural therapy (CBT), non-trauma-focused CBT and eye movement desensitisation and reprocessing (EMDR) are equally effective in treating PTSD. When measured at one to four months posttreatment, trauma-focused CBT and EMDR appear to be superior to non-trauma-focused CBT. Long-term follow-up data is limited, the studies are largely underpowered and there is a considerable unexplained heterogeneity between them (Bisson et al., 2013). In addition, gender differences have been suggested (Wade et al., 2016). Thus, current evidence needs to be interpreted with great caution; specifically, no conclusion on long-term effects can be made (Bisson et al., 2013). Although blinding of participants and healthcare providers may prove difficult in studies on psychological intervention, the remaining methodological challenges are potentially addressable in better designed studies in the future.

*'Psychotropic medication'* is the administration of drugs for psychiatric complaints. More than 50 randomised controlled trials have been conducted on psychotropic medication for PTSD. Still, a recent meta-analysis described the evidence base as inadequate (Hoskins et al., 2015). Only a minority of the studies included in the analyses provided sufficient information to determine the quality of the random sequence generation, allocation concealment, blinding and handling of incomplete data (Hoskins et al., 2015). Despite these notable weaknesses, current evidence demonstrate efficacy of treatment with the *selective serotonin reuptake inhibitors 'fluoxetine'* and *'paroxetine'*, and the *serotonin-norepinephrine reuptake inhibitor 'venlafaxine'*, over placebo in reducing PTSD symptoms. The effect sizes are small and inferior to those of psychological interventions. Thus, the clinical relevance remains unclear (Hoskins et al., 2015). Lastly, there is currently insufficient evidence to support the combination of psychological therapy and psychotropic medication compared to either intervention alone (Hetrick, Purcell, Garner, & Parslow, 2010).

***Extraordinary crisis response measures*** refers to a wide range of tailored help services that are not part of the regular healthcare services, but rather instigated as a particular response to a crisis and the challenges that are projected to follow. In the wake of a disaster, many countries are likely to adopt extraordinary crisis response measures to supplement regular healthcare services (Reifels et al., 2013). These measures are typically proactive, with the purpose of ameliorating negative impacts, facilitating healthy recovery, preventing development of PTSD, facilitating access to adequate healthcare, mitigating unmet needs and offering practical support (Reifels et al., 2013; Shultz & Forbes, 2014). Extraordinary crisis response measures may form part of a *'psychosocial crisis response programme'*.

The urge to intervene in the wake of traumatic exposures is not a recent development. The practice of *'debriefing'* may be traced back as far as World War I, when commanders would meet with their men following bloody battles and encourage them to share their traumatic experiences and emotions in order to promote health (Kearns, Ressler, Zatzick, & Rothbaum, 2012). No similar tradition existed for the civilian population. However, in the 1950s *'psychological first aid'* was first introduced and widely promoted as the appropriate response to civilian traumas (Drayer, Cameron, Woodward, & Glass, 1954; Tyhurst, 1951). Rather than focusing on debriefing after the traumatic event, psychological first aid aimed to support basic needs, provide psychosocial care and to protect those affected by the event from further threat (Bisson & Lewis, 2009). For nearly three decades the two approaches to traumatic exposure were kept largely separate. However, in the 1980s the *'critical incident stress debriefing'* method was developed for civilian traumas, based on experiences with debriefing practices in the US military (Mitchell, 1983). Known as *'psychological debriefing'*, this, and other similar methods, soon gained considerable popularity and were widely disseminated, despite a lack of evidence for their effectiveness or safety. In fact, neither single session psychological interventions (Rose, Bisson, Churchill, & Wessely, 2002; van Emmerik, Kamphuis, Hulsbosch, & Emmelkamp, 2002) nor multiple session psychological interventions (Roberts, Kitchiner, Kenardy, & Bisson, 2009) directed indiscriminately at all victims shortly after a trauma, were ever scientifically proven to be effective. On the contrary, evidence gradually emerged suggesting the opposite – that psychological interventions might actually have a negative effect on the health of trauma victims (Bisson, Jenkins, Alexander, & Bannister, 1997; Mayou, Ehlers, & Hobbs, 2000; Sijbrandij, Olff, Reitsma, Carlier, & Gersons, 2006). Due to its potentially harmful effects, psychological debriefing should no longer be performed as a part of crisis responses.

So, where does the field currently stand? Despite years of research, at present we do not have evidence to support the effectiveness of any intervention strategy (Bisson, 2014; Shultz & Forbes, 2014). Inaction is also problematic, as perceived lack of social support is associated with the development of PTSD. Thus, a *'trauma-informed'* evidence-base of expert opinions has been built up. At its fundament, five core principles guide the immediate practical, social and emotional support, as shown in *Box* 3. Unfortunately, the consensus offer little instruction on how they are to be achieved. In 2010, a consensus chaired by The European Network for Traumatic Stress (TENTS) worked out more detailed recommendations for the specific crisis response measures to be taken (Bisson et al., 2010). In broad terms, the TENTS guidelines advocate a multi-agency approach to a crisis response, in which safety, connectedness, calmness, self-efficacy, empowerment and hope are to be promoted, accompanied by general, physical and psychological medical support as needed (Bisson et al., 2010).

Box 3 Five essential elements of early to mid-level intervention in mass-trauma intervention

1. *Promote sense of safety*
2. *Promote calming*
3. *Promote sense of self- and collective efficacy*
4. *Promote connectedness*
5. *Promote hope*

*(Hobfoll et al., 2007)*

A number of practical manuals for trauma-informed *'psychological first aid'*, have been developed by WHO and others (Bisson & Lewis, 2009; National Child Traumatic Stress Network and National Center for PTSD, 2006; Shultz & Forbes, 2014; World Health Organization, War Trauma Foundation, & World Vision International, 2011). Furthermore, recommendations based on similar principles have been developed by the Inter-Agency Standing Committee (Inter-Agency Standing Committee (IASC), 2007) and the North Atlantic Treaty Organisation (North Atlantic Treaty Organisation (NATO), 2009). However, it should be stressed that, despite being widely embraced in response to disasters, effectiveness of psychological first aid has never been supported by firm evidence (Shultz & Forbes, 2014).

In Norway, psychosocial crisis response programmes are regularly set up by municipalities in response to adverse events that involves loss of lives or threat thereof, in line with current guidelines provided by the Norwegian Directorate of Health (2016). In the context of a larger disaster, psychosocial crisis response programmes were last organised in Norway on a major scale in 2004, in response to the Southeast Asian tsunami. This disaster affected a high number of Norwegian tourists abroad and crisis response programmes were set up across the country in order to support the survivors and their families, as they returned to their homes (Commission on the Tsunami Disaster in South Asia, 2005). A similar, decentralised crisis response programme was set up in the wake of the Utøya terrorist attack, as outlined in the Methods chapter (*The terrorist attack, p.* 36).

***Access to healthcare*** is the product of facilitators promoting and barriers restricting access to healthcare, together with qualities of the services provided, e.g. relevance, timeliness, continuity and effectiveness (Barker, Steventon, & Deeny, 2017; Gulliford et al., 2002). It has long been recognised that access to healthcare tends not to be provided where it is most needed. In fact, '*the inverse care law*', a term coined by the British GP Julian Tudor Hart (1927-2018), states that 'the availability of good medical care tends to vary inversely with the need for it in the population served' (Hart, 1971). A range of factors determining post-disaster access to healthcare have been identified. '*Andersen's behavioural model of health service use*' by the American health services researcher Ronald Max Andersen (1939 - ) is a commonly used framework for investigating determinants of post-disaster access to healthcare (Andersen, 1995). The model divides predictors of healthcare consumption into '*predisposing factors*', such as sociodemographic characteristics of the individual, '*illness-related needs factors*', such as perceived needs and symptom severity and '*enabling factors*', such as attitude towards health-seeking, availability of services and financial resources. Notably, the categories are not always mutually exclusive, as a single determinant may influence healthcare consumption in more than one way. For example, poor financial status may be a disenabling factor, but may also predispose an individual to healthcare needs. Analogously, having a distressed child may be an illness-related needs factor, but may also restrict access to healthcare in the parent.

Illness-related needs factors are generally considered to be the most potent determinants of healthcare utilisation (Andersen & Newman, 2005). However, current evidence suggests that individuals presenting severe distress symptoms in the wake of a terrorist attack may still be reluctant to seek help (Goldmann & Galea, 2014). This may be due to a number of factors, including personal barriers, such as stigma associated with mental healthcare services and unfamiliarity with the healthcare services (Elhai, North, & Frueh, 2005; Kantor, Knefel, & Lueger-Schuster, 2016; Rodriguez & Kohn, 2008; Welch et al., 2012). Unmet healthcare needs have been reported years after major terrorist attacks (Brewin et al., 2010; Call & Pfefferbaum, 1999; Stuber, Galea, Boscarino, & Schlesinger, 2006). Such needs may relate to availability, accessibility, as well as acceptability of services (Chen & Hou, 2002). In research, unmet healthcare needs may be assessed both as self-perceived unmet needs and as a combination of high levels of complaints and low levels of healthcare service utilisation.

Thus far, research into post-disaster healthcare consumption has largely relied on self-reported data. Thus, healthcare utilisation has often been assessed dichotomously (yes/no), rather than as continuous count data (Elhai, North, et al., 2005). However, as researchers are increasingly able to collect detailed healthcare data from national healthcare registries (Arnberg et al., 2015; Drogendijk et al., 2007; Rosendal, Mortensen, Andersen, & Heir, 2014; L. B. Strand, Mukamal, Halasz, Vatten, & Janszky, 2016), access data from administrative or insurance claim databases (Green et al., 2006; Sharp et al., 2016) or put specialised surveillance systems in place (Vandentorren, Paty, Baffert, Chansard, & Caserio-Schonemann, 2016), new research opportunities are emerging.

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## *The parental trauma*

Consensus holds that all those affected by a disaster should be provided with access to help services (Bisson et al., 2010). Thus, key questions are, who is affected and how do we reach out to them? Disaster victims may be a heterogeneous group, including survivors, bereaved, witnesses, close family and friends, and emergency personnel. Parents of survivors are a unique group of disaster victims who, as sources of social support for their children, may play a key role in recovery on a family level (Bonanno et al., 2010).

As previously mentioned, parental traumatisation may ensue both from '*witnessing*' the traumatic occurrences, e.g. standing outside the school, sports arena or nightclub being attacked, and from '*learning*' of the traumatic occurrences, e.g. though telecommunication with their loved ones or information provided by people at the site (American Psychiatric Association, 2013). Thus, parental traumatisation may ensue from a disaster, despite the parent neither being geographically present at the site of the disaster nor experiencing a physical threat to self. Previously, parents traumatised through experiencing life threat to their children have been referred to as being '*secondarily traumatised*' (Dirkzwager, Bramsen, Ader, & van der Ploeg, 2005; Yager, Gerszberg, & Dohrenwend, 2016) or as '*indirect victims of terrorism*' (Paz Garcia-Vera et al., 2016). As this terminology may avert attention from the fact that '*the parental trauma*' meets current definitions of a PTE, other researchers prefer to refer to parents as '*direct victims of terrorism*', on equal terms with the survivors themselves (Whalley & Brewin, 2007). In this thesis, the latter term is favoured.

Adding to the parental trauma, parents may experience uncertainty, powerlessness and fear as they may struggle to cope with their own distress while supporting their traumatised child. The relief of reunion may be accompanied by the shock of becoming reacquainted with an injured, distressed or poorly-functioning child. Many practical challenges may lie ahead, as the family transitions back into everyday life and returns to school, work and social arenas (Rokholt, Schultz, & Langballe, 2016).

Posttraumatic ill-health in parents, who experienced life threats to their children has previously been investigated in the context of natural disasters (Dyb, Jensen, & Nygaard, 2011; Hung, Lam, Chan, & Graham, 2013; Juth, Silver, Seyle, Widyatmoko, & Tan, 2015; Kilmer & Gil-Rivas, 2010), terrorist attacks (Kerns et al., 2014; Scrimin et al., 2006), severe illness of their child (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009; Nelson & Gold, 2012), sexual or physical abuse of their child (Dyb, Holen, Steinberg, Rodriguez, & Pynoos, 2003; Timmons-Mitchell, Chandler-Holtz, & Semple, 1996), traffic accidents affecting their child (Allenou et al., 2010; Kassam-Adams, Fleisher, & Winston, 2009; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2007) and deployment of young soldiers to areas of conflict (Dirkzwager et al., 2005; Slaven-Lee, Padden, Andrews, & Fitzpatrick, 2011). Substantial levels of distress have consistently been documented in all of these studies.

A majority of the previously conducted disaster-related studies on parental traumatization refers to *'shared trauma'* of the parent and the child, i.e. a trauma in which both parent and child are threatened by the same event. In a shared trauma, parent traumatisation pertains both to the threat to self and threat to the child. In a *'non-shared trauma',* on the other hand, parental traumatisation stems exclusively from learning of or witnessing the threat to their child.

In the particular context of a manmade disaster involving a non-shared trauma of parent and child, only two studies were identified, in addition to the publications derived from the Utøya study. The first study was a small study of 20 mothers who witnessed their children being caught in the Beslan school siege in 2005, from outside the school building (Scrimin et al., 2006). This study found high levels of posttraumatic stress in the mothers, similar to that of their surviving children. The second study was a registry-based study that investigated primary healthcare service consumption in more than 400 parents who had experienced their adolescent children being caught in a pub arson (intentionally lit fire) in the Netherlands. This study showed that the mothers and fathers of the survivors accessed their GPs soon after the disaster for a range of both mental and somatic health complaints (Dorn, Yzermans, Guijt, & van der Zee, 2007).

A small number of studies have addressed families, close relatives and friends of victims of terrorist attacks, as reviewed by Paz Garcia-Vera et al. (2016). Mean, weighted prevalence of PTSD was estimated as 29% within the first six months after the terrorist attacks and 17% in the subsequent six-month period. In line with these findings, a more recent study, which assessed family members and close relatives of victims of the terrorist attack in Paris, France, in 2015, reported PTSD in 5 out of 14 participants six months after the attack, as well as a range of somatic health complaints (Vandentorren et al., 2018). Thus, the overall, current evidence, although limited, suggests that significant others, such as parents, may suffer lasting ill-health from witnessing or learning of events affecting their children.

#

Terrorism currently features high on the public agenda. Although society seems eager to help, parents’ access to post-disaster healthcare has received little research attention thus far.

# Objectives

Overall objective of this thesis is to expand current knowledge on healthcare use in parents of disaster survivors. Each of the three papers included in the research paper collection assessed the range of healthcare services provided to mothers and fathers of the survivors of the 2011 Utøya terrorist attack.

**Paper 1** investigated whether the parents of the Utøya survivors were contacted by the crisis response programme. Were all parents approached? What characterised those who were not contacted? The paper also investigated whether higher levels of posttraumatic stress among the parents were associated with access to healthcare services from specialised mental healthcare providers.

**Paper 2** investigated changes in levels of parents' healthcare consumption following the terrorist attack, comparing three-year pre-disaster and three-year post-disaster primary and specialised healthcare consumption. Did frequency of healthcare service consumption increase in the wake of the terrorist attack? Did the number of parents accessing healthcare services increase? Finally, the paper assessed the reasons for parents accessing post-disaster healthcare services.

**Paper 3** investigated the role of posttraumatic stress in predicting post-disaster GP visits among the parents. Was parents' own posttraumatic stress associated with the frequency of their GP visits? Was posttraumatic stress in children associated with the frequency of their parents' GP visits? Was there an interaction between posttraumatic stress in the parent and the child related to frequency of GP visits?

# METHODS

## Design

This thesis builds on the Utøya study, a longitudinal observational prospective cohort study of the health and healthcare needs of the survivors of the 2011 Utøya terrorist attack and their parents. The overall study consisted of three waves of data collections, conducted by face-to-face interviews and questionnaires. Data analysed in the three papers included in this thesis was collected at *Waves 1* and 3, that is, at approximately three to five months and three years post disaster, combined with registry-based data on primary and secondary healthcare consumption in the three years before and the three years after the terrorist attack. An overview of the key features of the methodology is provided in *Table* 3.

Table 3 *Methodological overview of the three papers*

| | Paper 1 | Paper 2 | Paper 3 |
|---|---|---|---|
| *Design* | Cross-sectional | Longitudinal | Longitudinal |
| *Participants* | Parents | Parents | Parents and survivors |
| *Data source* | Self-reports (W 1) | Self-reports (W 3) & registry-based data | Self-reports (W 1+3) & registry-based data |
| *Main outcome measures* | > Psychosocial crisis response programme<br>> Specialised mental healthcare | > Primary healthcare<br>> Specialised mental healthcare<br>> Specialised somatic healthcare | > Primary healthcare |

*W = Wave*

# The terrorist attack

In the summer of 2011, nearly 600 adolescents and young adults were gathered on the Utøya Island for the annual summer camp of the Workers' Youth League. On July 22nd, a heavily armed gunman, disguised as a police officer, made his way to the island. Soon after his arrival he began a massacre of the young campers, who found themselves trapped on the tiny island with no means of self-defence, limited access to shelter and little chance of escape. The perpetrator pursued the youth for more than one hour without interruption. The shooting left 69 dead. Of the nearly 500 survivors, 35 sustained severe physical injuries (Bugge et al., 2015). The campers' mothers and fathers, all physically distant from Utøya, watched the massacre unfold from afar, their information coming from news coverage, telecommunication with their children and updates from the police and other emergency personnel.

The mass shooting on Utøya was ideologically motivated terrorist attack. Prior to committing this crime, the perpetrator published a neo-Nazi manifesto on the internet, and afterwards he declared that his motivation had been to attract the world's attention to his ideology (Berntzen & Sandberg, 2014; Leonard, Annas, Knoll, &

**Photos I-V** The Utøya Summer Camp

Tørrissen, 2014). The perpetrator was ruled mentally sane (*'compos mentis'*) in the subsequent trial (Oslo District Court, 2012).

After the Utøya terrorist attack, the young survivors were reunited with their families in more than 128 municipalities, in both rural and urban areas, throughout the country (Haga et al., 2015). The Norwegian health authorities soon issued detailed recommendations for the early crisis response to be provided by the affected municipalities (Karki, 2015). Multidisciplinary crisis teams were to ensure that all those affected by the terrorist attack were offered appropriate and timely psychosocial support in their home communities. Dedicated contact persons were assigned to the survivors, their parents and to the bereaved in order to provide continued psychosocial support throughout the first year post-disaster and to facilitate access to healthcare services if and when needed. Both measures were to be proactive, i.e. not to wait and see, but to actively contact those affected. The crisis response services following the Utøya terrorist attack were collectively termed *'early proactive outreach services'*.

Post-disaster healthcare services were provided by the regular healthcare system in Norway, which is a universal, publicly funded and hierarchical healthcare system. Healthcare needs are initially attended to by a GP. Further healthcare services, including specialised healthcare, are accessed through referrals only. Most people in Norway are registered in the regular GP scheme (99.6% in 2011, Norwegian Directorate of Health, 2012b). The GPs provide a wide range of general services, for mental, social and somatic health complaints, run the emergency primary healthcare services in the municipalities, coordinate and facilitate access to other help providers and act as the gatekeepers to specialised healthcare services (Ringard et al., 2013). The specialised healthcare services include the specialised mental and somatic healthcare services and are provided by physicians and psychologists in hospitals or in non-hospital clinics (Ringard et al., 2013). Further details on the Norwegian healthcare system are available in the English-language introduction booklet provided by the Norwegian Directorate of Health (Norwegian Directorate of Health, 2012a).

**Photo VI** The Utøya Island in the wake of the attack, from the parents' perspective

## Recruitment and participation

Participants of this study were the young survivors of the Utøya terrorist attack and their parents. Eligible participants were identified using police records of survivors rescued from the island (n=495). All survivors older than 13 years of age at the time of the shooting were invited to participate in the study. In addition survivors 13-33 years old (n=482), i.e. the youth who participated in the summer camp, were requested to name their parents, All parents nominated by the survivors were subsequently invited to participate in the study and referred to as mothers and fathers, regardless of their legal, social or biological status and of the total number of parents nominated by each survivor. Parents of older survivors (>33 year, N=8, adults visiting or working at the summer camp), parents of the youngest survivors (<13 years, N=4, children of adults visiting or working at the summer camp) and parents of one survivor who lived abroad were not invited to participate.

All parent participants included in this study shared a similar traumatic exposure: learning of the life threat to their children. Despite notable differences in the ages of their surviving children, all parent participants satisfied the criteria A of the PTSD diagnosis, according to DSM-IV. Thus, the parent participants were pooled and analysed as a single cohort. The parents participated independently of their children. Thus, recruitment of a parent did not require the participation of their child. *Waves* 1 and 2 were open cohorts, and all eligible survivors and their parents were invited to participate. *Wave* 3 was a closed cohort, and only included participants of the two former waves. Invitations were made in writing, and included information about the study and how to opt out. All survivors, as well as mothers and fathers of the younger survivors, born in 1992 or later, were invited to participate in structured face-to-face interviews. Parents of older survivors, born in 1991 or earlier, and parents not available for interview, participated through postal questionnaires. The age cut-off was applied due to logistical constraints; we did not have the resources to perform face-to-face interviews with all parents. The cut-off reflects the age by which most youth in Norway complete upper secondary school and usually move out of their family homes. In order to evaluate bias associated with mode of participation and age group of survivors, supplementary analyses comparing parents that participated through face-to-face interviews versus postal questionnaires and analyses comparing parents of school-aged survivors versus older survivors were performed for key variables.

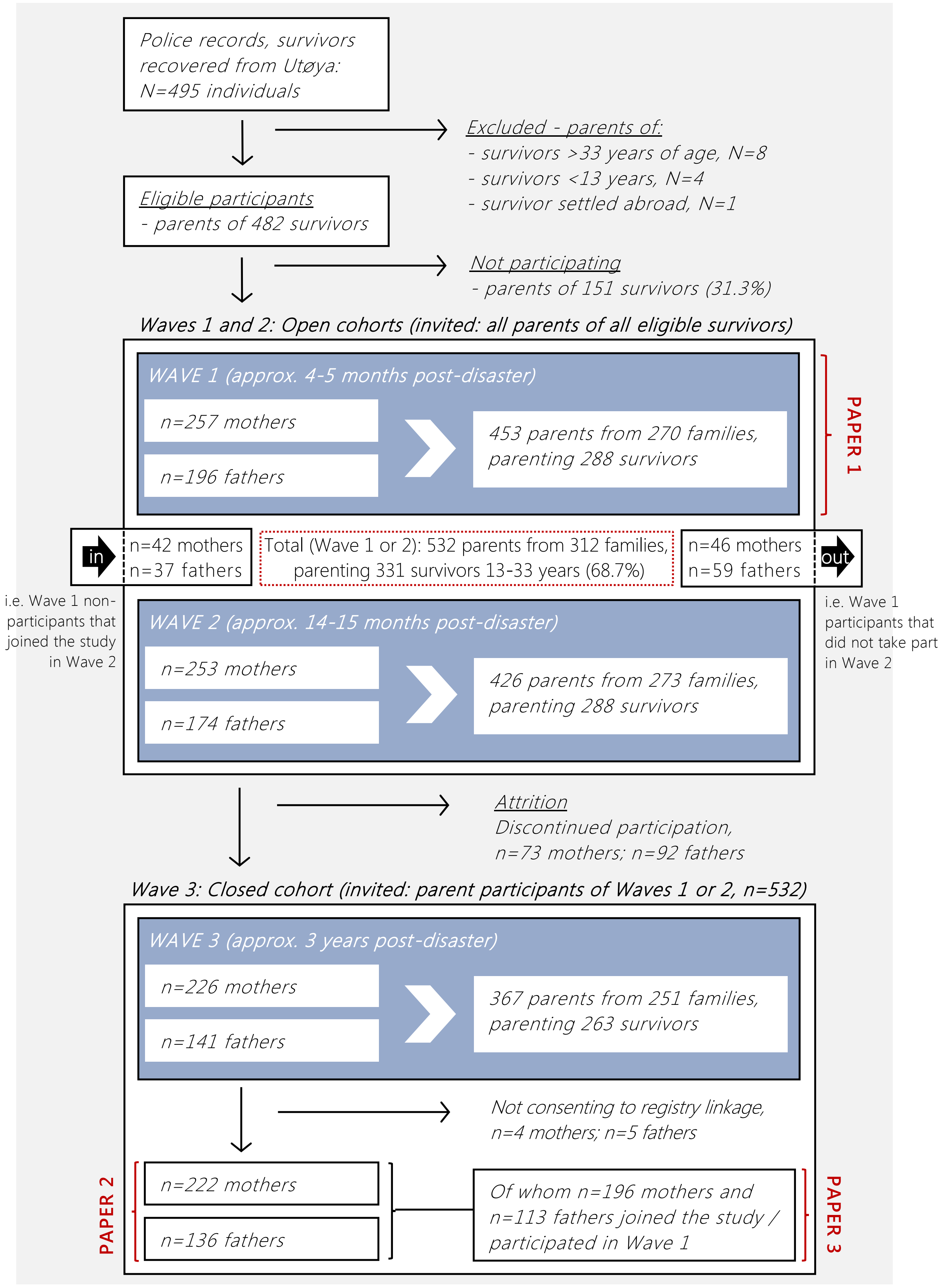
Face-to-face interviews were conducted in the home of the informant or at an alternative location selected by the informant. The interviewers were healthcare professionals, or had a relevant master's degree, and were largely recruited at NKVTS or from district psychiatric centres across the country. All interviewers attended a one-day training course with the project group both before and after each round of data collection. The face-to-face interviews lasted for approximately one hour and were audiotaped. The wording of the interviews and the questionnaires were identical for items assessed in this thesis. The questionnaires were distributed within the same period as the interviews were conducted.

An overview of the 532 parent participants across the three waves of data collection is presented in *Figure 2*. Red brackets in the figure indicate the specific parent sub-samples analysed in each of the three papers included in this thesis. As previously noted only data collected in *Waves 1* and 3 was analysed in this thesis. However, as participants of *Wave 3* were recruited from participants of *Wave 1* and/or *Wave 2*, information on all waves is provided in the figure for completeness. The red rectangle contains the total number of participants in one or more waves in this study. Notably, two thirds of the Utøya survivors (n=331, 68.7%) were represented by one or more parents in one or more waves of the Utøya study; 304 of these 331 survivors participated alongside their parents. *Table 4* summarises the number of survivors whose parents participated in each of the three parent samples analysed in this thesis.

Table 4 Overview of parent participants and the number of survivors cared for

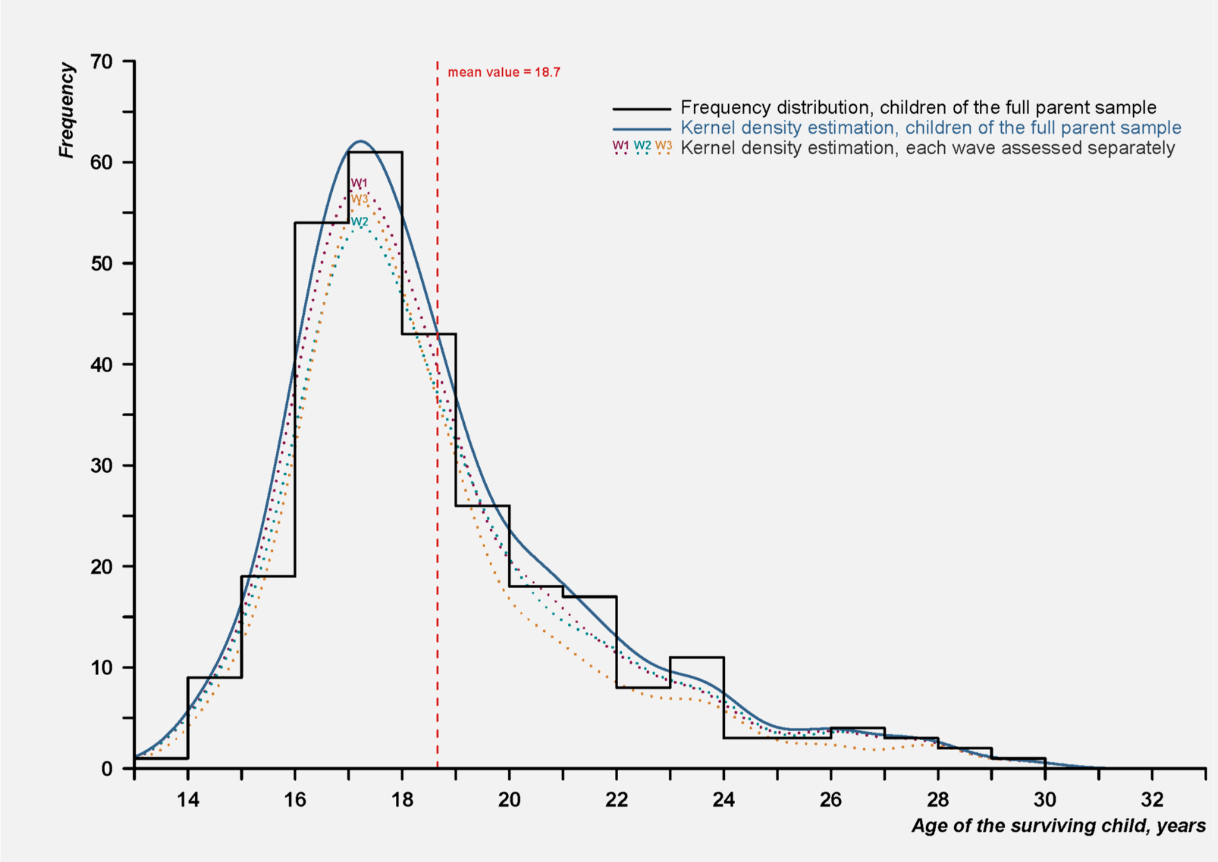
| | Parent participants | Survivors parented by the parent participants (% of all survivors 13-33 years, n=482) |
|---|---|---|
| *Sample of Paper 1* | 257 mothers<br>196 fathers | 288 (59.8%) |
| *Sample of Paper 2* | 222 mothers<br>136 fathers | 263 (54.6%) |
| *Sample of Paper 3* | 196 mothers<br>113 fathers | 227 (47.1%) |

Figure 2 Overview of parent participation in the Utøya study



A detailed breakdown of the age distribution of the 304 participating survivors is presented in Figure 3. Mean age was 18.7 (SD 2.8), and most (>95%) were 24 years old or younger at the time of the Utøya terrorist attack. A total of 96 survivors were older than 18 years; none were over 30 years old. Kernel estimations suggested similar age distributions across the three waves.

Figure 3 Age distribution of the survivors



*Age distribution of the 304 of the 311 survivors represented by the mother and father participants of this study; the ages of the remaining 27 survivors are not included, as these survivors opted not to participate alongside their parents. The frequency distribution (black histogram) refers to children of the entire parent sample. Kernel estimates were performed both for the entire sample (blue line), and for each wave separately (discontinued coloured lines). The estimates were adjusted to scale by multiplying each estimate by the number of individuals included in the estimate. W=Wave.*

Collection of data for *Wave 1* commenced in November 2011 and was largely completed (>95%) by mid-December 2011, five months after the attack. Collection of data for *Wave* 3 commenced in late March 2014, and was largely completed (>95%) by mid-July 2014, three years after the attack. A majority of the parent participants took part in face-to-face interviews (*Wave 1*, n=309 parents, 68.2% and *Wave* 3, n=284 parents, 77.4%). My contribution to data collection included face-to-face interviews and distribution of questionnaires in *Wave* 3.

# Non-participation and attrition

Non-participation refers to individuals that are eligible for participation, but that do not participate. Assessment of non-participation of parents is not straightforward. Families are not limited to one mother and one father, but may include a variable number of parents. Despite the exact size of the survivor population being known, the full size of the parent population remained unknown. However, as a number of survivors participated without a parent participating alongside them (n=51), in *Paper 1* we were able to compare the characteristics of survivors who had one or more parents participating with those who did not. We found that Norwegian origin, survivors' affiliation with the Workers' Youth League/Labour Party, young age of survivor and shared accommodation with offspring increased the likelihood of parents participating alongside their child.

Attrition refers to drop-out or discontinued participation in a longitudinal study. In this thesis, attrition specifically refers to participants entering the open cohorts of *Wave 1* and *Wave 2* and not completing the third wave. As demonstrated in *Papers* 2 and 3, attrition was associated with male gender. Additionally, attrition was significantly associated with participation through a questionnaire. Neither levels of early PTSR, level of education, perceived personal economy, country of origin nor whether living alone/with a partner were significantly associated with attrition.

## Measures

Variables analysed in *Papers* 1, 2 and 3 are presented schematically in *Table* 5 and discussed in more detail below. Excerpts from the interview manual are provided in *Appendix D.*

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### *Exposure measures*

Parents' exposure to the terrorist attack was assessed through self-reports at *Wave* 1. All parents were asked at what time they received information on the status of their child and at what time they were reunited with their child. The responses were recorded as a time and date, and later recalculated into continuous variables (hours after the attack).

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### *Psychological reactions measures*

**Posttraumatic stress reactions (PTSR)** were evaluated in both the children and their parents (in *Wave* 1) by the *University of California, Los Angeles Post-Traumatic Stress Disorder Reaction Index (UCLA PTSD-RI)* according to DSM IV, the current diagnostic manual at the time of the Utøya terrorist attack (Steinberg et al., 2004). The UCLA PTSD-RI consists of three parts. *Parts I* and *II* screen for trauma and peri-traumatic reactions (criteria A1 and A2). *Part III* evaluates severity of posttraumatic

**Table 5** Overview of variables included in Papers 1-3

| | Paper 1 | Paper 2 | Paper 3 |
|---|---|---|---|
| Exposure *(continuous data)* | | | |
| - time before receiving information about status of child | x | | |
| - time before being reunited with child | x | | |
| Psychological reactions *(continuous and categorical data)* | | | |
| - parents' PTSR score[1] and PTSD classification[2] | x | | x |
| - parents' HSCL-8 score[3] | x | | |
| - children's PTSR score[1] and PTSD classification[2] | | | x |
| Healthcare services | | | |
| *Self-reported (categorical data)* | | | |
| - psychosocial crisis response programme (crisis team and contact person) | x | | |
| - primary healthcare consumption | x | | |
| - specialised mental healthcare consumption | x | | |
| *Registry-based data (count data)* | | | |
| - primary healthcare consumption | | x | x |
| - specialised mental healthcare consumption | | x | |
| - specialised somatic healthcare consumption | | x | |
| Sociodemography *(continuous and categorical data)* | | | |
| - gender | x | x | x |
| - age at the time of attack | x | x | x |
| - country of birth | x | | x |
| - level of education | x | | x |
| - personal economy | | | x |
| - cohabitation with a partner | | | x |
| - family structure | x | | |

[1] *Posttraumatic stress reaction (PTSR) score refers to the 20-item University of California, Los Angeles Posttraumatic Stress Disorder Reaction Index (Steinberg, Brymer, Decker, & Pynoos, 2004).*

[2] *Posttraumatic stress disorder (PTSD) classification according to the 20-item University of California, Los Angeles Posttraumatic Stress Disorder Reaction Index (Steinberg et al., 2004).*

[3] *HSCL-8 refers to the 8-item version of the Hopkins Symptom Checklist-25 (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974).*

stress reactions according to the diagnostic criteria B-D. *Part III* contains 22 items, of which 20 items evaluate PTSD symptoms and 2 items evaluate associated features (fear of recurrence and trauma-related guilt). For brevity, the 20-item scale will be referred to as the UCLA PTSD-RI in this thesis. Each question was phrased in such a way that it explicitly related to the aftermath of the Utøya terrorist attack and to the reactions experienced in the month prior to the data collection. Responses were recorded on a 5-point Likert-type scale, ranging from never (0) to most of the time (4), in connection with a visual rating sheet presented to the participants (see *Appendix D*). Three symptoms were evaluated by two alternatively formulated questions; the questions attracting the higher frequency scores were included in the analyses of that symptom, reducing the total number of items to 17 (Steinberg et al., 2004).

First, continuous PTSR severity scores were calculated by averaging the frequency scores of the 17 items (possible range 0-4). Of note, a cut-off of ≥2.24 has previously been proposed for PTSD on this scale (38 points on the 17 items) (Steinberg et al., 2004). Second, probable PTSD was assessed according to the DSM-IV diagnostic criteria (American Psychiatric Association, 1994). Scores of 3 (often) and 4 (most of the time) were considered to represent a clinical complaint. Criterion *B* was considered to be satisfied with ≥1 such complaint, *C* with ≥3 such complaints and *D* with ≥2 such complaints. When all diagnostic criteria were satisfied (*B*, *C* and *D*), the participants were classified as having '*full PTSD*'. Participants with two criteria satisfied were classified as having '*partial PTSD*'. Missing values of ≤25% for a particular criterion were resolved by using the mean value of the remaining items. Cronbach's alfa of the scale was 0.89 to 0.93 for the three subsamples investigated (mothers, fathers and survivors).

**Depression symptoms** were evaluated by an 8-item version of the Hopkins Symptom Checklist-25 (Derogatis et al., 1974). The questions were formulated to refer to complaints experienced in the 2 weeks prior to the interview. Responses were recorded on a 4-point Likert-type scale, ranging from not at all bothered (1) to very much bothered (4). Mean scores were calculated using all 8 items. In the case of a cut-off being required for analyses, mean scores were calculated from the first 5 items of the 8-item instrument with a cut-off at ≥2.0 (B. H. Strand, Dalgard, Tambs, & Rognerud, 2003). Missing values of ≤25% of the scale were resolved by calculating the mean of the scores for the remaining items. Previous studies have demonstrated good psychometric properties of short versions of the Hopkins Symptom Checklist-25 in Norwegian study samples (B. H. Strand et al., 2003; Tambs & Moum, 1993). Cronbach's alfa of the total scale was 0.90.

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### *Healthcare services measures*

Data on engagement with the crisis response programme was assessed by self-reports at the time of *Wave 1*.

> - *'Did anyone from the crisis team or another representative of the municipality contact you right after the event?' (yes/no)*
> - *'Have you had a contact person in the municipality?' (yes/no)*

In *Paper 1*, data on healthcare consumption was collected through self-reports, in which the participant checked boxes indicating which services he or she had received since the terrorist attack, i.e. GP (yes/no), psychiatrist or psychologist in specialised mental healthcare services (yes/no).

In *Papers 2* and 3, data on healthcare consumption was obtained from registries. All individuals living in Norway are members of the national insurance scheme, which reimburses public and private healthcare providers in Norway. Thus, public registries on healthcare consumption were treated as comprehensive in respect to healthcare services provided to the participants, although it should be noted that any services paid for in full by the participants or obtained abroad would not be included.

**Primary healthcare services** were assessed using the Health Economics Administration (HELFO) database of reimbursement claims submitted by primary healthcare providers to the national insurance scheme. All services dating from 22nd July 2008 to 21st July 2014 were included, irrespective of whether they referred to services provided at a GP clinic, through house calls, by telephone or postal correspondence, by regular GPs or locum GPs, within regular office hours or when on-call. The services were subdivided according to type (*in-person* consultation or other services). Reasons for accessing primary healthcare services were recorded according to the International Classification of Primary Care (ICPC-2) (2005), and clustered according to health problem (Britt, Angelis, & Harris, 1998).

**Specialised healthcare services** were assessed by combining records from the Norwegian Patient Registry (NPR) – specialised healthcare reported by hospitals and hospital clinics – and the HELFO Database – specialised healthcare reimbursement claims submitted by private specialised healthcare providers to the National Insurance Scheme. All services reported by physicians and psychologists dating from 22nd July 2008 to 21st July 2014 were included, irrespective of whether services were provided in a public hospital, a private clinic, by telephone or mail and within regular office hours or not. Medical services provided by trained nurses or others on behalf of a physician or a psychologist were included. The services were divided into mental and somatic healthcare and by type of service (*in-person* consultation, admittance to hospital or other services).

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### *Sociodemography*

Sociodemographic information was collected in writing from all participants, either at the end of the face-to-face interview or as a part of the postal questionnaire.

- Gender (male/female) was collected through self-reports (in *Paper 1* gender was adjusted for, in *Papers 2* and *3* separate analyses were made).

- Age at the time of the Utøya terrorist attack was collected through self-reports and assessed as a continuous variable.

- Country of birth was based on self-reports in and dichotomised into categories '*Norwegian*' and '*non-Norwegian origin*'.

- Level of education was based on self-reports ('*none*', '*primary*', '*secondary*', '*vocational*' or '*higher education/university degree*') and dichotomised into '*higher education*' and '*no higher education*'.

- Personal economy was based on self-reports in which the parents rated their personal economy relative to the general population on a 5-point Likert-type scale ranging from much better (1) to much worse (5). Responses were dichotomised into '*average or better*' (responses 1-3) and '*below average*' (responses 4-5).

- Cohabitation with a partner (yes/no) at the time of *Wave 1* was based on self-reports. The participants were grouped according to family structure: '*intact family*' (parents not divorced), '*blended household*' (divorced parent, new partner) and '*single household*' (divorced parent, no new partner).

# Statistical analyses

Data included in this thesis comprises categorical-, continuous- and count variables. Descriptive statistics include frequencies, proportions, mean values and median values. Dispersions were assessed by standard deviations (SD), inter-quartile ranges (IQR), density plots (violin diagrams, *Paper* 2) and boxplots (*Paper* 3). The specific statistical analyses applied in the three papers are presented in *Table* 6.

**Table 6** Overview of statistical analyses and R software

| Analysis | R-package | Paper 1 | Paper 2 | Paper 3 |
|---|---|---|---|---|
| *Student t-test* | (stats) | x | | |
| *Chi-squared test ($\chi^2$)* | (stats) | x | x | |
| *Binary logistic regression* | (gee) | x | | x |
| *Negative binomial regression* | (MASS) | | | x |
| *Negative binomial hurdle regression* | (pscl) | | x | |
| *Bootstrap analyses* | (boot) | | x | |

*Statistical analyses were performed with R-version-3.0.3 and 3.1.2, R Foundation for Statistical Computing. Descriptive statistics of Paper 1 were performed with SPSS statistics V.20, IBM.*

Missing values remained low (<5%) and are indicated throughout the results sections of the three papers. Null hypotheses were rejected at significance levels of $p \leq 0.05$.

***Paper* 1** assessed categorical, dichotomous variables as the main outcome measure and binomial logistic regressions were applied. The dependent variables included contact with the proactive early outreach services (crisis team and contact person) and self-reported specialised mental healthcare services. Independent variables included gender, family structure, age, education, ethnicity, PTSR and HSCL-8. Clustering of parents (mothers and fathers parenting the same survivors) was addressed by a generalised estimating equations (GEE) procedure with an exchangeable correlation structure in the regression analyses, simplified when necessary for model stability. Multicollinearity of PTSR and HSCL-8 was observed (pairwise correlation coefficient, $r=0.82$). Thus, adjusted regressions of PTSR and HSCL-8 were performed in models without adjustment for each other. Student t-test and Chi-squared tests were used for simple comparisons.

***Paper*** 2 assessed registry-based count variables which exhibited excess zeros as the main outcome measure. Dependent variables were frequency of healthcare service consumption pre- and post-disaster. As the distribution was assumed to approximate a negative binomial distribution, a zero augmented negative binomial regression model, '*negative binomial hurdle regression*' (Zeileis A, 2008), was applied. Mothers and fathers were assessed separately and the regressions were adjusted for parent age. Age-adjusted predictions of frequency of parental healthcare consumption within each period of interest, i.e. pre-disaster, early aftermath and delayed aftermath, were made for an '*index parent*', defined as a mother or father of 47 years of age at the time of attack. Using these predictions, annualised rates of healthcare service consumption were estimated by dividing the predicted frequencies by duration of the time period investigated. Additionally, proportions of individuals accessing healthcare services within a six-month period before and after the attack were obtained by averaging semiannual values. Post- versus pre-disaster rate ratios were calculated by dividing the post-disaster estimates by the corresponding pre-disaster estimates. Bias-corrected and accelerated 95% CI for the ratios were generated based on 10,000 bootstrap replications. The full prediction procedure and rationale is discussed in more detail in the paper. Chi-squared tests were used for simple comparisons.

Of note, all analyses were made using a dataset encompassing *all healthcare services*, i.e. both *in person* consultations, as well as the range of other healthcare services provided, including telephone consultations, mail correspondence and simple prescriptions. As supplementary material, all analyses were repeated on a dataset including *in person* consultations only.

***Paper 3*** assessed registry-based count variables which did not exhibit excess zeros as the main outcome measure (the data did not exhibit excess zeros, as only the primary healthcare services were included). The distribution was assumed to approximate a negatively binomial distribution and regular negative binomial regressions were used to analyse associations between post-disaster primary healthcare consumption as dependent variable and PTSR as independent variable. In detail, frequency of parents' GP visits was regressed on the parents' and their children's PTSR, first separately, then in combination and, finally, by including an interaction. The analyses were performed separately in mothers and fathers and adjusted for pre-disaster GP visits and sociodemography (age at time of the attack, financial status, level of education, country of origin, whether living alone or with a partner and the number of child survivors at Utøya).

Of note, the paper analysed *frequency of GP visits* rather than *all services provided by* GPs. This was done in order to reduce the risk of inflated accuracy of association estimates that may otherwise have resulted from clustering of services (i.e. one GP visit may be directly related to services such as a phone call or mail correspondence). Binary logistic regressions were used for attrition analyses.

# Ethics

Preparedness for disasters builds on evidence-based knowledge. The need for knowledge may ultimately mandate research that involves human subjects, even in the distressing aftermath of a terrorist attack (O'Mathúna, 2010). As with all research involving human subjects, post-disaster research needs to be prepared, conducted and reported in accordance with the '*World Medical Association Declaration of Helsinki*' (World Medical Association, 2013). The importance of the research objectives must outweigh the risks and burdens associated with the projects and the highest ethical priority must be given to the protection of the participants (Collogan, Tuma, Dolan-Sewell, Borja, & Fleischman, 2004; Newman et al., 2017). A particular dilemma in post-disaster research is the need to initiate research shortly after a stressful event (O'Mathúna, 2010). Having recently experienced a trauma, the survivors and their families may be particularly vulnerable. Thus, post-disaster research projects need to balance the risks and benefits of research projects, both for participants and society, with particular care. In conducting the Utøya study, a number of measures were taken in order to minimise the risk of harming the participants. First, all participants received detailed written information about the study, prior to being contacted by an interviewer. The information included a clear statement about the purpose of the study and ways to opt out without being contacted by an interviewer. For any questions they had at this point, or later on in the course of the study, the participants were provided with the direct phone number of the research group. Second, a majority of the data was collected through face-to-face interviews with experienced healthcare professionals (mainly physicians and psychologists). All interviewers were trained in recognising posttraumatic emotional reactions and all interviews included assessment of suicidal ideation. The interviews were conducted in a safe and controlled environment, most often in the homes of the participants. Efforts were made to assign the same interviewer to the same informants in all three waves of data collection. Participants gave their written consent at each wave of data collection and were informed about the option to withdraw their consent at any time in the course of the study. Additional consent was obtained for collection of registry-based data. Third, all participants were asked whether they currently perceived a need for healthcare services and whether they were currently receiving the healthcare services they needed. If a participant reported unmet needs, the interviewer would facilitate access to the appropriate healthcare services. Following each wave of data collection, short reports were sent to the participants in order to inform them of the main findings. The participants received no compensation, monetary or otherwise.

Care of research staff is a second key priority in post-disaster research ethics. Inevitably, interviewers may be exposed to powerful emotions through interviews (Collogan et al., 2004). In the Utøya study, all interviewers were carefully selected and trained, and seminars were organised before and after each wave of data collection, in order for the interviewers to share their experiences and to communicate the results of the study.

Adequate protection of research data is imperative in all research involving human subjects and a prerequisite for maintaining privacy and confidentiality (World Medical Association, 2013). Data collected in the Utøya study was stored with the Services for Sensitive Data (*'Tjenester for sensitive data', TSD*), a data repository for collecting, storing and analysing sensitive data at the University of Oslo (Services for Sensitive Data, 2017). The repository is part of the national infrastructure for handling scientific data in Norway, and is in compliance with Norwegian regulations for data storage.

The study was approved by the Regional Committees for Medical and Health Research Ethics in 2011 (reference number #2011/1625 with principal investigator Professor Grete Dyb).

# OVERVIEW OF RESULTS

In the following, main findings from the three research papers are presented. For further details, including the full texts of Papers 1-3 and the supplementary materials, please refer to the *Appendices* A-C.

***Paper 1*** assessed factors associated with being contacted by the early crisis response programme, demonstrating that a majority of the parent participants had been contacted both by a crisis team (73.9%) and by a contact person in the municipality (73.0%). Failure of outreach was significantly associated with non-intact family structure (crisis team: OR=1.69, 95% CI 1.05 to 2.72, p=0.032) and non-Norwegian origin (crisis team: OR=2.39, 95% CI 1.14 to 4.98, p=0.021). Outreach was not significantly associated with gender (crisis team: p=0.075). Access to specialised mental healthcare services was significantly associated with higher levels of PTSR (OR=2.08, 95% CI 1.55 to 2.79, p<0.001) and symptoms of depression (OR=2.42, 95% CI 1.71 to 3.43, p<0.001), but not with the sociodemographic variables tested (p≥0.122).

***Paper 2*** assessed levels of parents' post-disaster primary and specialised healthcare service consumption. Compared to pre-disaster, the paper demonstrated a significant increase in levels of post-disaster primary healthcare service consumption in mothers (RR=1.97, 95% CI 1.76 to 2.23) and fathers (RR=1.73, 95% CI 1.36 to 2.29). Post-disaster primary healthcare service consumption remained significantly elevated in mothers in the delayed aftermath (six months to three years). For both mothers and fathers, the main reason for approaching the primary healthcare services was psychological health complaints.

For specialised mental healthcare, a significant increase in levels of post-disaster service consumption was demonstrated in mothers only (early: RR=7.00, 95% CI 3.86 to 19.02; delayed: RR=3.20, 95% CI 1.49 to 9.49). In fathers, an insufficient number of occurrences prevented reliable bootstrap analyses of specialised mental healthcare consumption. In specialised somatic healthcare, no significant change in levels of service consumption was found.

***Paper 3*** assessed early PTSR as a predictor for parents' GP visits. The paper demonstrated that parents' levels of early PTSR were significantly associated with higher frequency of GP visits in the early aftermath, both in mothers (RR=1.31, 95% CI 1.09 to 1.56) and fathers (RR=1.40, 95% CI 1.03 to 1.91). In the delayed aftermath, parents' levels of early PTSR were significantly associated with frequency of GP visits in mothers (RR=1.21, 95% CI 1.04 to 1.41), but not in fathers. Children's levels of posttraumatic stress reactions were not significantly associated with an increase in frequency of parents' GP visits. On the contrary, in the delayed aftermath, early posttraumatic stress reactions in children were significantly associated with a decrease in frequency of GP visits in mothers (RR=0.83, 95% CI 0.71 to 0.97).

# DISCUSSION

Disasters may impact people beyond the sites where they occur. This thesis demonstrated that the mothers and fathers of the young survivors of the Utøya terrorist attack experienced high levels of emotional distress in the wake of the attack and that they turned to the healthcare services for help. In the following, key findings, methodological challenges and clinical implications of the three papers will be discussed.

## Reaching out to parents

Healthcare needs in the wake of a manmade disaster may manifest abruptly and forcefully. Those affected may not be familiar with the range of healthcare services available to them and not know where to turn in order to request help. Psychosocial crisis response programmes are often established in an attempt to help bridge the gap that may exist between the individuals in need and the services available to them, despite a lack of evidence of their effectiveness. Programmes may typically aim to provide initial practical and psychosocial support, as well as to facilitate timely access to evidence-based healthcare services to those in need, by conscientiously approaching those affected by a disaster.

In the Utøya study, *Thoresen, Jensen, Wentzel-Larsen and Dyb (2016)* demonstrated that the parents of the Utøya survivors experienced high levels of emotional distress in the wake of the terrorist attack. This thesis suggests that the distressed parents experienced a wide range of healthcare needs. The findings are in line with the limited literature in the field (Salguero et al., 2011; Scrimin et al., 2006) and add weight to the notion that parents may suffer severe emotional traumatisation from learning of a life threat to their adolescent and young adult children. Parents should not be viewed solely as sources of social support for their surviving children, but also need to be considered as distinct '*victims*' or '*affected*' in their own right. High levels of parental distress provide a rationale for a more explicit focus on parents and their potential needs in future disaster plans. There is currently insufficient evidence to conclude on the helpfulness of proactive psychosocial crisis response programmes. Still, doing nothing may not be possible or publicly acceptable. In the event of a psychosocial crisis response programme being established, the option of reaching out to parents should be considered on similar terms as outreach to other groups of highly distressed individuals.

Reaching out to parents may not be straightforward. Lack of research in the field has left key questions unanswered. Who are the parents that we should reach out to? What are the barriers to outreach? A variety of family arrangements, relations and social networks make clear-cut definitions of '*close family*' difficult. Specifically, the term '*parents*' may be ambiguous and include a variety of adults, and not necessarily the two biological progenitors of the child. Although a majority of the participants in the Utøya study were biological mothers and fathers, it is worth noting that the study sample also included other adults, with a variety of biological, legal and social statuses.

A majority of the parent participants reported that they had been included in the psychosocial crisis response programme. This finding suggests that municipalities across the country succeeded in reaching out to many of the parents. Nonetheless, approximately one in five parents included in the study reported that they had not been approached by anyone in their municipality. This contrasts with a similar study of outreach to the survivors, in which a near-complete inclusion in the very same crisis response programme was reported (Dyb, Jensen, Glad, Nygaard, & Thoresen, 2014). In other words, whereas nearly all survivors were included in the crisis response programme, a substantial number of their parents missed out. Failure of outreach was not random. Parents of non-intact families, i.e. families in which the biological mother and father did not share a household, and parents of non-Norwegian origin were significantly less likely to be contacted by the psychosocial crisis response programme than parents of intact families and parents of Norwegian origin. Minority parents may be particularly vulnerable in the wake of a disaster. Thus, these findings call for particular attention to sociodemographic factors when planning and conducting future post-disaster outreach programmes. The particular groups at risk may vary between different countries and disaster settings. Nonetheless, this thesis underscores the need for healthcare personnel to consider the prospect of sociodemographic barriers restricting outreach when implementing proactive psychosocial crisis response programmes.

There may not be one simple explanation for the systematic differences in outreach observed in this study. Perhaps the municipalities were not sufficiently attentive to the complexity of modern family structures? Perhaps parents not living permanently with the survivor were considered less in need of proactive outreach services? Limited resources may have restricted the capacity of some municipalities in running a comprehensive outreach programme, and cultural barriers, language difficulties or low level of familiarity with the Norwegian healthcare system may have influenced outreach specifically to parents of non-Norwegian origin. More research is needed in order to better understand and, hopefully, find ways to overcome barriers to outreach in the future.

# Post-disaster primary healthcare

General, non-specialised healthcare services may play an important role in supporting individuals affected by a disaster. Primary healthcare providers, such as GPs, may deliver much needed general healthcare services for both somatic and psychological health complaints, as well as provide the practical support necessary for the entire family to settle back into everyday life. There is currently limited research on the extent to which parents turn to their primary healthcare providers for help following a disaster threatening the life of their children; to my knowledge, only one study has been conducted (Dorn, Yzermans, Spreeuwenberg, & van der Zee, 2007). This study of the parents of Dutch adolescent fire victims, demonstrated that post-disaster rates of early primary healthcare acquisition were significantly higher among the parents than in unaffected community controls. In line with this finding, this thesis documents that parental post-disaster primary healthcare consumption in the wake of the Utøya terrorist attack increased significantly, both in terms of number of services accessed and in terms of the number of parents accessing the services, supporting the notion that parents do turn to their GP for help following disasters that affect their children. It is important and necessary that GPs are advised to prepare accordingly.

In order to prepare, GPs may need to know the number of services that will be in demand, at what time they will be needed and for how long. Soon after the Utøya terrorist attack, a majority of both mothers and fathers approached their regular GP. A sudden increase in primary healthcare consumption was observed. Later, levels of primary healthcare consumption largely levelled out, although they remained significantly higher than pre-disaster levels in mothers throughout the three-year aftermath. Thus, GPs need to prepare for an increase in demand for primary healthcare services by parents of survivors, both in the early and delayed aftermath of a terrorist attack.

The next question is, what health complaints should GPs prepare for? Following the Utøya terrorist attack, early increase in parents' primary healthcare consumption was largely attributable to psychological health complaints. Nonetheless, somatic health complaints, such as musculoskeletal, cardiovascular and respiratory complaints were also frequently recorded among the parents. Thus, GPs should be advised to prepare for an increase in both mental and somatic healthcare needs.

Studies of parental traumatisation have frequently been performed on single gender samples, i.e. in mothers only (Allenou et al., 2010; Cabizuca et al., 2009; Slaven-Lee et al., 2011; Timmons-Mitchell et al., 1996). Single gender samples limit interpretability of findings, as gender may play an important role both as a predictor of post-disaster healthcare needs and of healthcare seeking behaviours. For example, in a Danish population-based sample, gender differences in baseline primary healthcare consumption were found, in part, to be attributable to female-specific healthcare needs, such as gynaecological diagnoses, but also to gender differences in prevalence of other health complaints, including mental health complaints (Jorgensen, Andersen, Tjonneland, & Andersen, 2016). Furthermore, gender differences in doctor-seeking behaviours for psychological health complaints have previously been suggested, in terms of men being more reluctant than women to access healthcare (Harris et al., 2016). In the aftermath of the Utøya terrorist attack, the mothers were observed to consume more primary healthcare services than the fathers. This observation may speak to gender differences in prevalence of posttraumatic health complaints (Olff, Langeland, Draijer, & Gersons, 2007; Tolin & Foa, 2006). It may also speak to gender differences in barriers to accessing healthcare. Further research is needed in order to determine whether the fathers of the Utøya survivors may perhaps have experienced more post-disaster barriers to accessing primary healthcare services than the mothers. In any case, the gender differences observed in this thesis are a clear reminder of the importance of including both mothers and fathers in research on the posttraumatic health and healthcare consumption in parents.

Absolute levels of post-disaster primary healthcare consumption may only be cautiously compared between different healthcare settings, as baseline levels of primary healthcare consumption vary greatly between countries (Eurostat, 2017). In the particular context of parental traumatisation, scarcity of studies further limits comparisons. However, when compared to the one study available, the study of the parents of the Dutch arson survivors (Dorn, Yzermans, Spreeuwenberg, & van der Zee, 2007), primary healthcare consumption among the parents of the Utøya survivors was found to be somewhat higher in the early aftermath, although not in the years thereafter.

It should be noted that consultations with GPs do not necessarily indicate that parents' healthcare needs are recognised, let alone adequately provided for. Post-disaster ill-health may easily be misinterpreted or underestimated in the primary care setting. Specifically, PTSD may be challenging to recognise in the primary care context (Ehlers, Gene-Cos, & Perrin, 2009) and GPs may not be adequately trained or have the necessary expertise (Munro, Freeman, & Law, 2004). This thesis did not address the clinical contents of the services provided; thus, no conclusion can be made on their appropriateness.

Primary healthcare providers may play an important role in providing general healthcare services to both mothers and fathers in the wake of a disaster. GPs need to prepare for both short- and long-term increases in demand for services and for attending to both psychological and somatic health complaints. More research is needed on potential barriers to accessing the primary healthcare services and on the clinical contents of post-disaster primary healthcare services.

# Familial context of help seeking

Even as parents fall victim to a trauma that threatens the lives of their children, they are expected to step up, taking on a leading role in caring for their child and in the recovery process of the family. Being important sources of social support for their children, the role of parents is critical in the transition back to normality in most families (Bonanno et al., 2010). However, at the same time, parents may be struggling with their own stress reactions and healthcare needs. Thus far, determinants of healthcare consumption have largely been investigated in terms of discrete sociodemographic and illness-related characteristics of individuals affected by a disaster (Andersen, 1995; Elhai, North, et al., 2005). The role of social or familial networks in post-disaster healthcare consumption has not previously been addressed, despite emerging evidence suggesting that posttraumatic stress reactions of parents and children may mutually influence and interact with one another (Morris, Gabert-Quillen, & Delahanty, 2012).

In the context of the Utøya terrorist attack, this thesis suggests an intricate relationship between healthcare consumption in parents and the health complaints of their surviving children. First, parents' own posttraumatic stress reactions were significantly associated with higher frequencies of early GP visits among both mothers and fathers. Second, in the delayed aftermath, higher posttraumatic stress reactions of the child were significantly associated with lower levels of GP visits among mothers. Third, an interaction between parent and child distress was suggested, both in the early and the delayed aftermath, although significant overall interaction of the models was not demonstrated. In other words, both mothers and fathers accessed their GPs more frequently in accordance with higher levels of their own stress reactions, whereas higher levels of child's stress reactions predicted significantly less frequent GP visits in mothers in the delayed aftermath. As it seemed unreasonable to assume that child's distress would have had a protective effect on the mothers, lowering their post-disaster healthcare needs, two alternative explanations were proposed. First, mothers of the more traumatised survivors may have benefitted from healthcare services provided to their traumatised children, thereby reducing their own need for general healthcare services. Second, mothers of the more traumatised children may have faced more obstacles to accessing their GP, e.g. they may have had to focus their attention on providing for their traumatised child, rather than on acquiring help for their own healthcare needs.

It should be noted that the correlations demonstrated need to be interpreted with great caution. Alternative sources of general healthcare cannot be ruled out. On the other hand, these findings represent novel evidence suggesting that levels of distress in one family member in the wake of a terrorist attack may potentially restrict access to GPs in another family member. These findings thus urge for increased attention to the familial and social context of post-disaster health complaints and healthcare consumption in parents. Future research should ideally seek to include entire families in studies of post-disaster healthcare consumption, as well as other sources of social support, such as close friends, schools and workplaces.

## The role of specialised services

Psychologists and psychiatrists are widely recognised as playing a key role in providing for a subset of disasters victims (Arnberg et al., 2015; Boscarino, Adams, & Figley, 2004; Brewin et al., 2010; Brewin et al., 2008; Lowe, Sampson, Gruebner, & Galea, 2016; Rodriguez & Kohn, 2008; Stuber et al., 2006). Nonetheless, to my knowledge, utilisation of specialised mental healthcare services in parents traumatised through experiencing a disaster that threatens the life of their children have thus far not been addressed.

In the early aftermath of the Utøya terrorist attack, one in five mothers and nearly one in ten fathers accessed specialised mental healthcare services. Early contact with specialised mental healthcare services was significantly associated with higher levels of parents' early distress. In other words, specialised mental healthcare services appear to have been provided on a needs basis, i.e. to the parents presenting elevated levels of distress. Those accessing specialised mental healthcare services were found to be largely new to the services, i.e. had not received specialised mental healthcare services within the three years prior to the terrorist attack. Previously, post-disaster access to specialised healthcare for individuals not already enrolled in the services, has been shown to rely on a pre-established relationship with a regular primary healthcare provider (Boscarino, Adams, Stuber, & Galea, 2005). In the context of the Utøya terrorist attack, all parents included in this study were found to have a designated GP through the regular GP scheme at the time of the attack. Furthermore, most parents had been in contact with their designated GP once or more within the three-year period preceding the attack, as well as in the early aftermath. Thus, it seems reasonable to assume that referrals of parents to the specialised healthcare services in the wake of the Utøya terrorist attack were largely handled by GPs, in line with regular referral practices in Norway. However, it is possible that normal referral practices may have been bypassed in the wake of the Utøya terrorist attack, due to the unprecedented nature of the event. Specifically, it may be that providers of the crisis response programme facilitated direct access to specialised mental healthcare.

It should be noted that although specialised mental healthcare was found to be provided to individuals presenting elevated levels of distress, at the time of *Wave 1* nearly one in ten parents were found to present levels of distress indicative of clinical PTSD or clinical depression diagnoses, without having accessed any healthcare services in the wake of the terrorist attack. This finding may indicate early unmet healthcare needs in a subgroup of the most distressed parents.

# Methodological considerations

Scientific validity refers to the degree to which a study may '*truthfully*' answer a research question with a reasonable and statistically well-founded conclusion (Bland, 2015; Frigessi, Moger, Scheel, Skovlund, & Veierød, 2006). In this thesis, results were considered in terms of internal and external validity, as is briefly outlined in the following.

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### *Internal validity*

The extent to which conclusions based on statistical associations are warranted, i.e. that the findings of the study are attributable to the factors being tested, is frequently referred to as their '*internal validity*' in statistical literature (Bland, 2015; Frigessi et al., 2006). Study design, confounding variables and systematic errors/bias may all limit the internal validity of a study.

**Study design** refers to the conditions under which the data material of a study has been collected. The three papers included in this thesis had an observational study design, which is a study design that observes groups of individuals without attempting to influence the outcome being measured (Bland, 2015; Frigessi et al., 2006). By design, observational studies confer inferior internal validity compared to experimental studies. There is no randomisation of participants and no controlled study environment in which the pre-specified intervention is being tested. Thus, all interferences in observational studies need to be interpreted cautiously and in the light of plausible confounding variables.

Confounding variables may threaten validity of the results presented in this thesis on three different levels, due to the conditional risk of post-disaster health complaints. First, confounding variables may pertain to the risk of having a child participating in the summer camp at Utøya. Second, confounding variables may pertain to the risk of developing healthcare needs, given having had a child on Utøya. Third, confounding variables may pertain to the likelihood of accessing healthcare, given experiencing healthcare needs. As sociodemographic factors may confound all three levels, all analyses included in this thesis were adjusted for key sociodemographic factors. Gender was either adjusted for or analysed in separate models. Factors such as whether or not the parents lived with one or more of the survivors and the amount of time that parent and child spent together were not adjusted for, due to insufficient information.

*Paper* 1 had a cross-sectional design, whereas *Papers* 2 and 3 had a longitudinal design. The latter allowed for a more detailed assessment of the order of events and for adjustment for pre-disaster values, thus strengthening internal validity of the findings.

**Selection bias** refers to the systematic errors resulting from systematic dissimilarities between the population of interest and the study sample being investigated (Bland, 2015; Frigessi et al., 2006). Selection bias may result from biased recruitment and biased attrition.

In many disaster studies, lack of overview of the victim population and reliance on '*convenience sampling*' is a major source of selection bias (Bonanno et al., 2010). In the Utøya study, all survivors were easily identifiable and we were able to extend invitations to all. Their parents were less accessible. Recruitment of the parents was carried out through letters of invitation posted to the home address of the survivors. Selection bias may have resulted from a number of factors, as outlined in *Box* 4.

**Box 4** Key factors that may have biased participation in this study (selection bias)

*a) Whether or not the parent was identified by their child as a 'parent'.*

*b) Whether or not parents identified as parents received the invitation. In cases where parent and child did not live together, the written invitation was sent to the registered address of the survivor. Thus, delivery of the written invitations to the parents relied on the survivors forwarding the invitation.*

*c) Whether or not the parent was willing to participate.*

*d) Attrition from the study (Papers 2 and 3 only).*

e) *Whether or not the parent consented to sharing registry-based healthcare data (Papers 2 and 3 only).*

No information was available for the families from which neither parent nor child participated. Thus, we had limited data to inform *points a-c*. However, as we had sociodemographic data on all child participants, regardless of parents' participation, we were able to compare children of participating parents with children of non-participating parents. In brief, Norwegian origin, survivors' affiliation with the Workers' Youth League/Labour Party, young age of child and shared accommodation of parent and child favoured parental participation.

Sociodemographic data was readily available for dropouts and non-dropouts alike. Thus, *points d-e* were more accessible for analyses. By comparing participants of *Wave 3* to those who discontinued the study after the first or the second wave, *Papers 2* and *3* demonstrated that attrition among parents in the third wave was associated with male gender, but not to any of the other sociodemographic variables tested or to levels of PTSR.

The response rates of parents could not be directly assessed. Despite the survivor population being known, the extent of the parent population remained unknown. As a surrogate, parent participation was evaluated in terms of the proportion of survivors being represented by one or more parent participant. The parent samples assessed in the three papers included in this thesis represented approximately half of the Utøya survivors.

**Information bias** refers to inaccurate measurement or misclassification (Bland, 2015; Frigessi et al., 2006). Information on PTSR and depression symptoms was collected through self-reports, derived from face-to-face interviews and questionnaires. Of note, self-reported data is prone to information bias due to inaccurate or subjective recollection, or so-called *'recall bias'*. Furthermore, limiting validity, *Wave 1* was collected over several months. Fluctuations in mental health complaints throughout this period may have introduced information bias. In order to improve the accuracy of the self-reports, a number of measures were taken. First, validated instruments were used. Second, questions were formulated to refer to a specific time period immediately preceding the interview. Third, as participants responded to each item of the two instruments, they were presented with a graphic representation of the frequency scales, illustrating the response options. Fourth, scores were assessed as continuous values, wherever possible, in order to avoid arbitrary cut-offs.

Posttraumatic stress reactions were assessed both in survivors and in their parents. In order to increase comparability of scores between the two groups, one common instrument was favoured. As some of the survivors were as young as 13 years old, an instrument developed for assessment of posttraumatic stress reactions in adults was deemed unsuitable. Thus, an instrument developed for assessment of posttraumatic stress reactions in adolescents was selected. The UCLA PTSD-RI has previously been validated in American youth samples, and widely applied in studies of children and adolescents worldwide, but has not been validated in an adult sample nor in a Norwegian sample. In fact, at the time of the Utøya terrorist attack, no instruments assessing posttraumatic stress reactions had been validated in a Norwegian sample. This limits the validity of the PTSD classification reported in this thesis. All information on probable PTSD diagnosis included in this thesis is reported along with information on partial diagnosis (two out of three criteria satisfied) and the continuous PTSD severity score and all statistical analyses are based on the continuous PTSD severity scores, rather than probable diagnosis. It should be noted that the UCLA PTSD RI has been validated with a different threshold to most other 0-4 PTSD instruments. Whereas most instruments use an intensity or frequency score of ≥2 for determining whether a PTSD symptom should be considered '*clinical*', i.e. whether it satisfies a DSM-IV PTSD criterion or not, the UCLA PTSD-RI is validated with a frequency score of ≥3 ('*much of the time*' and '*most of the time*'). The higher threshold applied in the UCLA PTSD RI potentially increases the risk of false negatives (under-diagnosis) and potentially decreases the risk of false positives (over-diagnosis) compared to other instruments. At the same time, it should be noted that scores obtained through different instruments may not be directly comparable, e.g. as '*intensity scores*' and '*frequency scores*' of different instruments may refer to different '*characteristics*' or '*quality*' of the symptoms assessed. In American youth samples, the UCLA PTSD-RI has been validated with good psychometric properties, with an estimated sensitivity of 0.93 and specificity of 0.87 (Steinberg, 2004).

As outlined in the method section, the data in this study was collected either through face-to-face interviews or through postal questionnaires. The wording of the questionnaire was identical to the face-to-face interview. Nonetheless, the questionnaire did not allow for any immediate questions or clarifications. Previous research has suggested that mode of data collection may be significantly associated with differences in response patterns of health self-assessment instruments (Feveile, 2007). Additionally, in this study mode of data collection was related to age of the survivors; only parents of younger survivors (born 1992 or later) were invited to participate through a face-to-face interview. Thus, mode of participation and age of survivors represent two major and interrelated sources of information bias. Analyses were performed, as outlined in the supplementary material to *Paper 1*, in order to address this risk of bias. First, mode of participation was assessed in parents of the younger participants. Responses from parents of school-aged survivors who participated through face-to-face interviews were compared with responses from parents of school-aged survivors who had been unable to participate through face-to-face interviews, thus participating though questionnaires instead. No significant differences were demonstrated in terms of item non-completion, levels of posttraumatic stress reactions or symptoms of anxiety and depression. Second, responses of parents of younger versus older survivors were compared. Responses from parents of school-aged survivors who participated through face-to-face interviews were compared with responses collected through questionnaires from parents of the older survivors. No significant differences were demonstrated in terms of item non-completion, levels of posttraumatic stress reactions or symptoms of anxiety and depression. These findings are in line with further work in our department on parental distress (Holt et al., 2017). Nonetheless, as systematic differences may not be ruled out, mode of participation and age of survivor remain major sources of potential information bias in this study. Also, it should be noted that attrition between the waves was significantly associated with having participated through a questionnaire.

Registry-based data on healthcare service consumption was collected from public databases. These databases contain reports submitted by the healthcare providers at the time of the healthcare provision. The use of registry-based healthcare data eliminates recall bias and interviewer bias. However, other sources of information bias may have influenced results. The healthcare providers may have failed to report the services provided or the data reported may have been influenced by the purpose of the reporting scheme, e.g. implication for funding, management policies, research opportunities and so forth. It has been argued that the latter is more likely to affect the detailed contents of the information reported, such as the diagnoses assigned or the procedures performed, to a higher degree than information on whether or not a consultation took place (Schmidt et al., 2015). Ageing may influence levels of healthcare consumption. Thus, all regressions on parental healthcare consumption were adjusted for parents' age. However, as we did not have an age-matched control group for the findings presented in this thesis, we were unable to perform more detailed analyses of healthcare consumption in relation to age or ageing of the parents. This is a notable limitation in this study.

Taken together, confounding variables and bias threaten the internal validity of the conclusions presented in this thesis. Although a number of measures were taken in order to address these challenges, all associations need to be considered with caution. Specifically, no causality may be concluded on the basis of an observational study design.

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### External validity

The extent to which findings are generalizable to other populations or situations may be referred to as external validity (Bland, 2015; Frigessi et al., 2006). External validity is a fundamental strength of observational studies, as they are '*naturalistic*' in terms of being conducted without introducing any artificial stimuli or interventions in a '*real world context*'. However, the real world context that is being observed may vary greatly between different countries, traumas and victim populations. Thus, observational studies, however naturalistic they may be, are not necessarily generalizable.

The parents included in this study were mothers and fathers of adolescents and young adults. Reflecting the observed age structure of the young participants of the Utøya summer camp, the age range of the survivors was wide and a variety of family arrangements were observed in our material. This heterogeneity limits generalisability of the findings presented in this thesis. Specifically, the age structure deviates from that of school shootings, in which survivors are generally younger and more age-homogenous (one or a few classes affected), and from that of disasters affecting communities, which may include a wider range of individuals, such as younger children, older adults and the elderly. More research is needed in order to determine the extent to which this study may inform parental distress and healthcare consumption beyond the age group being investigated.

The findings presented in this thesis may be most applicable to a context of similar traumatic exposure, including parents learning of or witnessing their children being caught in a shooting spree or a terrorist attack at a leisure venue, e.g. in a night club, concert hall or sports arena. The extent to which the findings may be generalizable to other kinds of traumatic exposures, such as a family member being harmed in a natural disaster, major accident, traffic accident or by serious illness is yet to be addressed.

Healthcare services accessed in the aftermath of the Utøya terrorist attack were provided by the universal, publicly funded healthcare services in Norway. The findings may thus be most applicable to a comparable healthcare context. Specifically, the findings may be most applicable to healthcare systems in which GPs assume the role of *'first-line'* providers and gatekeepers to specialised healthcare services, and where a similar psychosocial crisis response programme is established in response to adversity.

# Clinical implications

The clinical implications of this thesis may be considered both in terms of *'healthcare planners'* and in terms of the individual *'healthcare providers'*.

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### ***Healthcare planners***

- Parents may experience a wide range of healthcare needs in the wake of a terrorist attack threatening the lives of their children. Healthcare planners need to be aware of and attentive to the needs of parents when planning psychosocial crisis response programmes.

- Non-intact families and parents of ethnic minority backgrounds may be at increased risk of being left out of the proactive crisis response programmes. Healthcare planners need to prepare for overcoming post-disaster sociodemographic challenges to outreach in the wake of disaster.

- The demand for both primary and specialised healthcare services may increase in the aftermath terrorist attacks. Healthcare planners need to prepare for facilitating timely access to the services required, and appropriate services once accessed.

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### ***Healthcare providers***

- In the wake of a terrorist attack, high numbers of parents may turn to their GPs for help. GPs need to prepare for the increase in demand.

- GPs may play an important role in providing for post-disaster healthcare needs. Thus, GPs need to acquire the necessary evidence-based competencies. Appropriate training for GPs needs to be a part of an overall plan for future disaster management, including what competencies are needed by whom, as well as how these competencies should be obtained, maintained and audited.

- Parents of survivors may be restricted from accessing appropriate healthcare for their own healthcare needs. Thus, in the wake of traumatic events, healthcare providers need to be particularly attentive to the families of survivors.

## Future directions

Resilience to disasters relies on evidence-based knowledge guiding appropriate practices. As previously discussed, the current evidence base on intervention strategies for PTSD is fragmentary and, in part, of insufficient scientific quality. More research is urgently needed. Future research should address the full chain of post-disaster healthcare services through well-designed, methodologically robust studies. Specifically, the role of psychosocial crisis response programmes in facilitating appropriate healthcare services to those in need should be investigated. Are such programmes at all helpful? Also, strategies for management of PTSD and related health complaints should be evaluated in studies with longer follow-up and the potential role of GPs in the delivery of evidence-based interventions should be further explored.

There is a complex relationship between unmet healthcare needs and associated factors, such as gender, family networks, social networks, health literacy, previous experiences with the healthcare services, mental health, migration status, history of victimisation and more. New statistical methods, such as structural equation modelling, may allow for better understanding of these complex relationships. Furthermore, the use of alternative sources of data, relevant for health and functioning, including registry-based data on drug prescription, welfare service utilisation, employment status and education achievements, as well as alternative research methods, including mixed methods research designs, may provide valuable insights into heath and healthcare needs in trauma-exposed families.

Our understanding of posttraumatic ill-health has changed considerably over the years. It is likely to continue to evolve further with future research. New intervention options are likely to emerge. At present, developments in the use of information technology and internet-based interventions show promise (Kuester, Niemeyer, & Knaevelsrud, 2016; Lewis et al., 2017; Morland et al., 2017; Olff, 2015). Information technology has multiple advantages in the wake of disasters, as it may provide new therapeutic opportunities, require less of therapists' time and be more easily scalable to a surge in demand. A novel field within ongoing research is the visuospatially demanding computer game *'Tetris'* from 1984. It has recently made an unlikely comeback as a potential future candidate for early PTSD intervention (Iyadurai et al., 2017). Although it raises interesting questions, at present no conclusions can be made on its effectiveness or on its potential future role in the management of PTSD. Another emerging field within ongoing research is pharmacological prophylaxis (Sijbrandij, Kleiboer, Bisson, Barbui, & Cuijpers, 2015). Pharmacological prophylaxis with hydrocortisone has shown some promise, although insufficient evidence currently prevents any conclusions on its effectiveness (Birur, Math, & Fargason, 2017; Sijbrandij et al., 2015).

Society may be eager to help those affected by terrorist attacks. Are we perhaps too eager? Trauma-informed crisis response programmes are commonly instituted in the early aftermath of disasters, despite limited evidence of their helpfulness. Are we wasting precious resources? Are we at risk of interfering with normal healing processes? The history of early PTSD interventions has taught us that not all attempts to help are for the best. It is imperative to invest in crisis response measures that are likely to be effective, and have the greatest impact on the lives of those affected by trauma. Evidence-based interventions, including trauma-focused CBT and EMDR, should be at the core of any disaster plan. Emphasis should be placed on pre-trauma implementation. Relevant healthcare providers, be they specialists, GPs or others, should be provided with the appropriate competencies prior to a disaster taking place.

Throughout his career, the Norwegian professor of social medicine Per Fugelli (1943-2017) warned against the health risks of what he called a '*vision zero*' in health, in which too much is promised and too much is asked (Fugelli, 2006). Do we have an unrealistic expectation of treatment for emotional traumas? Does our perhaps overly optimistic focus on the potential benefits of crisis responses, early outreach programmes and PTSD interventions lead to disappointment and bitterness, rather than promoting health? When planning future research, we need to constantly reflect upon our current practices. At a minimum, any strategy adopted must confer little or insignificant risk of causing harm and should never delay or preclude the access to appropriate evidence-based care.

# CONCLUSION

This thesis investigated access to post-disaster healthcare for the parents of the survivors of the Utøya terrorist attack. Most parents turned to their GPs for help soon after the attack, largely for psychological health complaints. Additionally, a minority of the parents received specialised mental healthcare services. Parents' post-disaster healthcare consumption was associated with their own levels of distress. A majority of the parents were approached by the psychosocial crisis response programmes, although parents of non-Norwegian origin and of non-intact families ran an increased risk of being left out.

The healthcare services may hold an important key to health in parents in the wake of a disaster and need to prepare accordingly. Primary healthcare providers should prepare for both psychological and somatic healthcare needs arising in parents in the early and delayed aftermath. Specialised mental healthcare providers should be prepared to care for the most severely traumatised. Whether or not psychosocial crisis response programmes have a role to play as a supplement to regular healthcare services remains to be decided. However, when reaching out to parents, sociodemographic barriers to outreach need to be considered.

**- Jon Magnus Haga -**

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# APPENDIX

# PAPER 1

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# Early postdisaster health outreach to modern families: a cross-sectional study

Jon Magnus Haga,[1,2] Lise Eilin Stene,[1,3] Tore Wentzel-Larsen,[1,4] Siri Thoresen,[1] Grete Dyb[1,2]

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[1]Norwegian Centre of Violence and Traumatic Stress Studies, Oslo, Norway
[2]Faculty of Medicine, University of Oslo, Institute of Clinical Medicine, Oslo, Norway
[3]Department of Social Pediatrics, Women and Children's Division, Oslo University Hospital, Oslo, Norway
[4]Centre for Child and Adolescent Mental Health, Eastern and Southern Norway, Oslo, Norway

**Correspondence to**
Jon Magnus Haga;
jon.magnus.haga@medisin.uio.no

## ABSTRACT

**Objectives:** This study investigated whether the early outreach programme following the Utøya massacre reached out to the parents of the young survivors. Additionally, we explored whether specialised mental healthcare services were provided to parents presenting elevated levels of PTSD and depression reactions.

**Design:** Cross-sectional survey, face-to-face interviews and questionnaires.

**Setting:** Norway, aftermath of the Utøya massacre, 4–7 months postdisaster.

**Background:** Following the Utøya massacre, proactive early outreach programmes were launched in all municipalities that were affected, facilitating access to appropriate healthcare services.

**Participants:** A total of 453 parents of the Utøya survivors aged 13–33 years took part. Overall, 59.8% of the survivors were represented by one or more parent in our study.

**Main outcome measures:** Engagement with the proactive early outreach programme (psychosocial crisis teams and contact persons in the municipalities), utilisation of healthcare services (general practitioner and specialised mental healthcare services) and mental distress (UCLA PTSD-RI and HSCL-8).

**Results:** A majority of the participants reported contact with the proactive early outreach programme (crisis team, 73.9%; and contact person, 73.0%). Failure of outreach to parents was significantly associated with non-intact family structure (crisis team: OR 1.69, 95% CI 1.05 to 2.72, $p=0.032$) and non-Norwegian origin (crisis team: OR 2.39, 95% CI 1.14 to 4.98, $p=0.021$). Gender of the parent was not significantly associated with failure of the outreach programme ($p\geq0.075$). Provision of specialised mental healthcare services was significantly associated with higher levels of PTSD (OR 2.08, 95% CI 1.55 to 2.79, $p<0.001$) and depression (OR 2.42, 95% CI 1.71 to 3.43, $p<0.001$) and not with the sociodemography ($p\geq0.122$).

**Conclusions:** Proactive early outreach strategies may be helpful in identifying healthcare needs and facilitating access to the required services in a population struck by disaster. Our findings prompt increased attention to the complexity of family structures in reaching out universally to modern families following a disaster.

## Strengths and limitations of this study

- The nature of the traumatic exposure, the ordered aftermath, and the perfect separation of parents and survivors allow the assessment of indirect exposure of families to terrorism.
- We were able to recruit a high number of caregivers, including multiple caregivers of the majority of the survivors and high numbers of paternal caregivers.
- Our figures represent the combined picture of crisis response programmes in a total of n=128 municipalities.
- A majority of the data was collected in face-to-face interviews with experienced clinicians.
- All analyses are correlational. No causality can be demonstrated.

## INTRODUCTION

In the summer of 2011, Norway experienced a terrorist attack on a summer camp of political youth, gathered on a small island, Utøya, for political workshops and social recreation. One single perpetrator, responsible for the bombing of the governmental quarters <2 h earlier, started a shooting spree immediately on his arrival to the island. The youth were trapped with the perpetrator on the island for more than 1 h with no means of self-defence, limited access to shelter and scarce chances of escaping. The attack left 69 dead. Nearly 500 survived, of which 35 sustained severe physical injuries. Parents, siblings, relatives and friends were confined to live media reports as the atrocities unfolded. Following the attack, all survivors were returned to their families in communities across all regions of Norway.

Persistent mental ill-health, notably post-traumatic stress disorder (PTSD) and depression, may frequently trouble survivors of terrorism for years following the trauma.[1 2] Recent terrorism specifically targeting children and adolescents have prompted particular attention to the impact of terrorism on youth.[3–6] However, terrorism may have detrimental effects not only on those directly exposed, but also on their close ones, particularly their parents. Studies of parents caring for chronically ill[7 8] and acutely ill[9 10] children and children exposed to sexual abuse[11] have demonstrated high levels of PTSD and depression. Analogously, studies on parents of UN peacekeepers and mothers of US military personnel deployed to Iraq have demonstrated substantial distress years following redeployment of offspring from hostile environments.[12 13] Indirect impact of terrorism on parents of young survivors is, however, still largely unaddressed.

In order to facilitate access to appropriate care and minimise unmet healthcare needs in a population affected by a disaster, evidence-informed recommendations for proactive early outreach have been made in a number of recent consensus documents.[14–16] Early outreach may target unmet needs by providing initial psychosocial and practical support, monitoring healthcare needs, and facilitating access to healthcare services.[17–19] In contrast to regular healthcare, the idea of outreach is to engage proactively and universally with the population of target, with regard neither to medical history nor to levels of distress. However, the recommendations do not address the needs of the indirectly exposed families of the terror victims.

Following the shooting in Utøya, a national proactive early outreach programme was established. The programme included both municipal interdisciplinary psychosocial crisis teams and a designated contact person for each survivor, their families and the families of the deceased. Crisis teams were to contact all affected families promptly following the attack and offer initial support. The contact persons were to monitor healthcare needs throughout the first year following the attack through a minimum of three waves of formalised screening assessments at 5–6 weeks, 3 months and 1 year. The geographical dispersion of the survivors of the terrorist attack warranted implementation of early outreach programmes in a total of 128 municipalities of all five regions of the country.

Modern families frequently diverge from that of cohabiting mothers and fathers, and pose particular challenges for outreach to parents of young survivors. Divorce of parents, introduction of step-parents and presence of half-siblings and step-siblings give rise to variability in the number of caregivers, number of households and gender composition of households of modern families. Gender roles in transition and ethnic and cultural diversity may further add to the complexity of modern family arrangements and challenge implementation of outreach strategies. In regular practice, healthcare providers are inexperienced with initiating contact with individuals who are not already in touch with the healthcare services and may be unfamiliar with the variability of modern family structures. Healthcare providers may be reluctant to engage proactively and indiscriminately with a target population, rather than individual patients, and may perhaps be prone to favouring individuals with registered health problems. Moreover, for ethnic minorities, proactive outreach may potentially be postponed or indeed neglected due to inexperience with or constraints to access to interpreters or bilingual healthcare providers.

The aims of this study were to investigate whether the early outreach programme following the Utøya shooting reached out to the parents of the survivors and whether it reached out equally well to mothers and fathers, traditional and non-traditional family structures, parents of both Norwegian and non-Norwegian origin, and across different levels of distress. Additionally, we explored whether specialised mental healthcare services (MHS) were indeed provided to those presenting elevated levels of PTSD and depression reactions.

## METHODS

### Design

This cross-sectional study assessed outreach and healthcare to the parents/caregivers of the youth survivors (13–33 years) of the 2011 Utøya summer camp massacre at 4–7 months following the terror attack.

### Procedures

Invitations to participate in the study were sent to the addresses of the survivors. Subsequently, the survivors were contacted by telephone and asked about the contact information of their caregivers. The caregivers identified by the survivors were then contacted and asked if they were willing to participate in the study. All caregivers are referred to as parents, without regard to their legal, social or biological status or number of caregivers nominated per family.

Invitations were distributed through mail which included general information about the study and on how to opt out. Parents of the survivors born in 1992 or later were invited to participate in individual semistructured face-to-face interviews by healthcare professionals in their own homes or in an alternative location at the request of the participant. The interviewers were trained in a 1-day session prior to conducting interviews. The interviews lasted approximately 1 h and were audiotaped. Parents of older survivors (born in 1991 or earlier) and parents who were not available for an interview participated by questionnaires. Information on sociodemographic variables, contact with the early outreach programme and the utilisation of healthcare services were collected through questionnaires for all parents, either at the end of the interview or as a part of the postal questionnaire. Interviews started early November 2011 and were largely completed (>95%) by mid-December 2011, 5 months after the attacks. Questionnaires were distributed by mail at the time of the interviews. By mid-February 2012, 95% of the data of both modalities had been collected.

All participants provided a written consent. The study was approved by the Regional Committees for Medical and Health Research Ethics in Norway.

## Participants

The police records of survivors recovered from Utøya included a total of 495 names. Parents of older survivors (>33 years of age, N=8), parents of the youngest survivors (<13 years, N=4) and parents of one survivor settled abroad were not invited to the study. In total, parents of 482 survivors were eligible participants of this study.

A total of 453 parents from 270 families, representing 59.8% (n=288) of the survivors of Utøya (aged 13–33 years) participated, of which 16 families had more than one child in Utøya. A majority of the 270 families participated with two parents or more (65.9%, n=178). In nearly half of the families, parents were divorced or separated (43.0%, n=116). Divorced, non-cohabiting parents were recorded as separate households. A total of 315 distinct households were identified. Households were subdivided into 'intact family' (parents not divorced), 'blended household' (parent divorced, new partner) and 'single household' (parent divorced, no new partner). Norwegian origin, survivors' affiliation with the Worker's Youth League/Labor Party (the political party being targeted through the attacks), young age of offspring survivor and shared accommodation with offspring survivor favoured parental participation (see online supplementary table S1). Addressing the mode of participation, we found that paternal caregivers and caregivers of non-intact families were more likely to be unavailable for participation through face-to-face interviews than maternal caregivers and intact families (see online supplementary table S2). Neither measure of distress was significantly associated with mode of participation.

## Measures

*Proactive early outreach* was assessed by two items: 'Did anyone from the crisis team or other representative of the municipality contact you right after the event?' (yes/no) and 'Have you had a contact person in the municipality?' (yes/no).

*Health service utilisation* was assessed by inquiring about whether the subject any time following the events in Utøya received care from a regular general practitioner (GP, yes/no) or psychiatrist or psychologist in specialised MHS (yes/no).

*Traumatic stress exposure* of all parents included having an offspring threatened with violent death in Utøya. Additional exposure was assessed by inquiring at what time the parent was informed about the condition of his/her offspring, and at what time they were reunited (date and time). Additionally, we inquired about telephone contact (voice or text) with offspring while the shooting was ongoing (yes/no), physical injury and hospitalisation of offspring (yes/no), hospitalisation of a close friend or family member (yes/no), fatality of a close friend or family member (yes/no) and whether the parent, at the time of the Utøya attack, had concurrent concerns about family or friends being affected by the bombing of the Government Quarter in Oslo that had taken place earlier in the day (yes/no).

*Post-traumatic stress reactions (PTSR)* during the past month were evaluated by the 20-item University of California, Los Angeles PTSD Reaction Index (UCLA PTSD-RI)[20] according to the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).[21] Responses were recorded on a five-point Likert-type scale, ranging from 0 (never) to 4 (most of the time). Three of the items had two alternative formulations, with the highest frequency score used to calculate the total score. Hence, 17 scores constituted the total symptom scale score (possible range 0–68). Criterion A (exposure to potentially traumatic event) was satisfied in all participants of this study. Criteria B (intrusion), C (avoidance) and D (arousal) were derived by grouping items related to these categories. Inquiries on PTSR were formulated so as to explicitly relate to the terrorist attack. Scores of 3 (often) and 4 (most of the time) of each item were taken to indicate presence of a clinical symptom. Probable PTSD diagnosis (full PTSD) was considered on all diagnostic criteria being satisfied (ie, criterion A, ≥1 item criterion B, ≥3 items criterion C and ≥2 items criterion D). With two criteria being satisfied, partial PTSD was considered in patients falling short of full diagnosis. Full and partial probable diagnoses were taken to represent clinically significant distress. Cronbach's α of the total scale was 0.92.

*Symptoms of depression and anxiety* during the past 2 weeks were evaluated with an 8-item version of the Hopkins Symptom Checklist-25 (HSCL-25).[22] Responses were recorded on a four-point Likert-type scale, ranging from 1 (not at all bothered) to 4 (very much bothered). Average scores of all 8 items were calculated for each parent. Short versions of the HSCL-25 have previously been used in Norwegian population surveys and have shown high correlations with the 25-item scale and good psychometric properties.[23] [24] The subscale HSCL-5 was employed to identify clinically significant distress, with a clinically validated cut-off of ≥2.0. Cronbach's α of the total scale was 0.90.

*Sociodemographic* variables included age at the time of attack, country of birth (Norwegian/non-Norwegian origin), level of education (none, primary, secondary, vocational or higher education/university degree), current employment ≥50% (yes/no), and absence from work during the past 3 months (yes/no). Financial situation was assessed on a five-point Likert-type scale, where the parents rated the economy relative to the general population, ranging from 1 ('much better') to 5 ('much worse'). The responses were dichotomised into 'average or better' and 'below average'. Participants born outside Norway were considered to be of non-Norwegian origin and thus, as an ethnic minority in

Norway. Most non-Norwegian participants in our study were born outside of Europe.

Information on cohabitation of parent and survivor (yes/no), age of offspring survivor, and affiliation with the Worker's Youth League/Labor Party (yes/no) was collected from a set of interviews with the survivors that were conducted in parallel with this study.[3]

### Statistics

Point estimates of continuous data are reported by the mean or median value, with dispersion reported by SD and IQR. Logistic regression was used for bivariate analyses of categorical variables.

Missing values of the data set remained ≤5% throughout analyses, unless stated otherwise. Missing values ≤25% within sum scores of PTSD and HSCL-8 were resolved through calculations of mean scores of the remaining items.

On the basis of the hypotheses generated a priori, we designed a total of three logistic regression models. The first two models investigated proactive early outreach. The third model investigated specialised mental healthcare. Degrees of freedom available for each model were based on the number of observations in the smallest groups of the dependent variables. Clustering of members of the same families was addressed by the *gee*-procedure with an exchangeable correlation structure in the regression analyses (simplified when necessary for model stability). Independent variables of all models included gender (male/female), family structure (intact/non-intact), age, education (higher education/no higher education), ethnicity (Norwegian/non-Norwegian origin), PTSR and HSCL-8. Multicollinearity of independent variables was assessed independently of the family clustering and identified by pair-wise correlation coefficients (r) and variance inflation factors (VIF). As multicollinearity of PTSD-RI and HSCL-8 (r=0.82) was observed, the adjusted regressions of PTSD-RI and HSCL-8 were estimated without reciprocal adjustment to one another. The adjusted regressions of PTSD-RI and HSCL-8 thus include the sociodemographic variables of each model only. Adjusted regressions for the remaining variables of each model include the complete set of variables with both measures of psychopathology. Null hypotheses were rejected at significance levels of p≤0.05.

Regression analyses were performed with R V.3.0.3 (R Foundation for Statistical Computing), with the package gee for *gee* analysis. Descriptive statistics were performed using SPSS statistics V.20, IBM.

## RESULTS

The 453 parents who participated in this study were of both genders (males 43.3%, n=196) with a mean age of 48.3 years (SD=6.55), largely of Norwegian origin (98.1%, n=413, missing n=4), and residing in all regions of Norway at the time of the attack. The participants were well educated, with more than half (57.8%, n=260, missing n=6) of the parents holding a university degree, and they reported high employment rates (89.5%, n=400, missing n=6) with largely on average or above average financial situations (87.0%, n=388, missing n=8). The majority of the participants were identified as biological parents (95.6%, n=433). Nevertheless, a great heterogeneity of family arrangements were identified (table 1), and nearly half of the 270 families represented by the parent participants were of a category other than intact nuclear families, with two cohabiting biological parents (43%, n=116).

Traumatic exposure of the parents included having a child threatened by violent death in Utøya. Moreover, more than half of the parents reported having had telephone contact with their offspring while the shooting was ongoing (58.2%, n=263, missing n=1). Concurrent concerns of family or friends being affected by the bombing attack on the Government Quarter was reported by 39% (n=176, missing n=2). Median time from the onset of the attacks until parents were informed on the condition of their offspring was 2.6 h (IQR=2.1–3.4 h, missing n=25). Within 5 h, 90.7% (n=388) of the parents had got such information. A majority of the survivors (79.9%, n=362, missing n=4) were reunited with their families within the following day. In the aftermath of the terrorist attack in Utøya, hospitalisation of offspring was experienced by 18.8% (n=82, missing=17) of the parents. Moreover, physical injury to other family/close friend resulting in hospitalisation (11.2%, n=49, missing n=17) or in fatality (17.5%, n=79, missing n=2) added to the trauma of the parents.

The mean score of PTSR was 1.13 (range: 0–4, SD=0.76, 95% CI 1.06 to 1.20, missing n=2). Partial PTSD was reported by 18.3% (n=83) and full PTSD by 7.1% (n=32) of the parents. The mean score of depression was 1.69 (range: 1–4, SD=0.63, 95% CI 1.63 to 1.75, missing n=4), with 28.9% (n=133) scoring above the cut-off of ≥1.85. Nearly half of the parents reported

**Table 1** Parent participants by gender, type of caregiver and family structure (n=453)

| | Gender | | |
|---|---|---|---|
| | **Female** | **Male** | **Total** |
| All | 257 (56.7%) | 196 (43.3%) | 453 (100%) |
| Caregiver | | | |
| Biological | 251 (97.7%) | 182 (92.9%) | 433 (95.6%) |
| Household* | | | |
| Intact family | 146 (56.8%) | 130 (66.3%) | 276 (60.9%) |
| Blended | 51 (19.8%) | 40 (20.4%) | 91 (20.1%) |
| Single | 58 (22.6%) | 26 (13.3%) | 84 (18.5%) |
| Other | 2 (0.8%) | | 2 (0.4%) |

*Intact family: cohabiting mother and father; blended and single households: divorced or widowed parents with or without new partner.

**Table 2** Overview of proactive early outreach and the use of health services by the parents (n=429–448)

| | Proactive early outreach | | Healthcare services | |
|---|---|---|---|---|
| | **Crisis team** | **Contact person** | **GP** | **MHS** |
| Dichotomous variables (number; %, yes) | | | | |
| All parents | 331 (73.9) | 324 (73.0) | 206 (47.0) | 146 (34.0) |
| Mothers | 200 (77.8) | 190 (75.1) | 151 (60.2) | 91 (37.6) |
| Fathers | 131 (68.6) | 134 (70.2) | 55 (29.4) | 55 (29.4) |
| Parent of intact family | 210 (77.2) | 211 (78.4) | 121 (45.7) | 94 (36.3) |
| Parent of other family | 121 (68.8) | 113 (64.6) | 85 (49.1) | 52 (30.6) |
| Norwegian origin | 310 (75.2) | 304 (74.1) | 187 (46.5) | 131 (33.3) |
| Non-Norwegian origin | 20 (57.1) | 19 (57.6) | 18 (51.4) | 14 (40.0) |
| Higher education | 190 (73.4) | 184 (71.6) | 117 (46.2) | 91 (35.8) |
| No higher education | 140 (74.5) | 139 (74.7) | 88 (47.8) | 54 (31.0) |
| Continuous variables (mean, yes vs no) | | | | |
| Age (years) | 48.1 vs 48.9 | 48.1 vs 48.8 | 47.2 vs 49.1 | 47.4 vs 48.6 |
| PTSD: range 0–4 | 1.15 vs 1.04 | 1.13 vs 1.09 | 1.36 vs 0.92 | 1.38 vs 0.98 |
| HSCL-8: range 1–4 | 1.71 vs 1.66 | 1.69 vs 1.68 | 1.92 vs 1.49 | 1.92 vs 1.57 |

GP, regular general practitioner; MHS, specialised mental healthcare services.

absence from work in the aftermath of the attacks due to health problems (41.5%, n=161, missing n=12).

Table 2 summarises variables that were hypothesised to be associated with early outreach and the use of healthcare services. Although the programme of early proactive outreach engaged with a majority of the parents, paternal caregivers and parents of non-intact families and of non-Norwegian origin reported to have less frequently received outreach by their municipalities. Consultation with their regular GP following the attacks was reported by nearly half of the parents; this was more prevalent among women than men. Moreover, a third reported contact with specialised MHS. We found that proactive early outreach by a contact person was significantly associated with utilisation of a GP (OR 1.70, $\chi^2$ p=0.016), but not of specialised MHS (OR 1.03, $\chi^2$ p=0.899).

A series of three adjusted regression models tested the variables hypothesised to be associated with early outreach and the use of specialised healthcare services.

Models A and B (figure 1A, B) tested associations of variables that were hypothesised to be associated with receiving proactive early outreach. Female gender was significantly associated with having been contacted by a crisis team in unadjusted regression. In adjusted multivariable analyses, however, intact family structure, but not gender, was significantly associated with having been included in both forms of proactive early outreach, and non-Norwegian origin was significantly associated with having been contacted by the crisis teams. Stress reactions, on the other hand, were not significantly associated with engagement with the proactive outreach programme.

Model C (figure 1C) tested associations of variables that were hypothesised to be associated with utilisation of specialised MHS. Utilisation of specialised MHS was significantly associated with PTSR and depression, but not with either of the sociodemographic variables included in our study.

Finally, we assessed utilisation of specialised healthcare services among parents with the highest levels of distress. Clinically significant levels of distress defined as partial or full PTSD or HSCL-5 above cut-off were taken to indicate the need for healthcare services. Although, clinically significant distress and the use of specialised healthcare services were reported by nearly equivalent numbers of parents (35.1%, n=158, missing n=3 vs 34%, 146, missing n=24) and the use of GP was reported by nearly half of the parents (47%, n=206, missing n=15), a total of 8.3% of the parents reported a combination of significant distress and no contact with any healthcare service (n=36) (table 3). Reversely, a total of 33.6% of the parents reported utilisation of healthcare services without presenting distress at the time of data collection (n=146).

## DISCUSSION

Crisis response typically focuses on survivors of a disaster and may easily overlook affected individuals not present at the site of an attack. The first aim of this study was to investigate whether the early outreach following the Utøya shooting managed to reach the parents of the young survivors. Our data suggest that the outreach programme succeeded in reaching out to a large proportion of the parents, and that the programme engaged equally well with mothers and fathers. Encouragingly, the outreach was not significantly associated with levels of either PTSR or depression, in line with the principle of universal early outreach. However, modern families are heterogeneous and changeable. Nearly half of the parents in our sample were of a category other than that of a traditional cohabiting mother and father. The outreach following Utøya failed in engaging with parents who did not live together and parents of ethnic

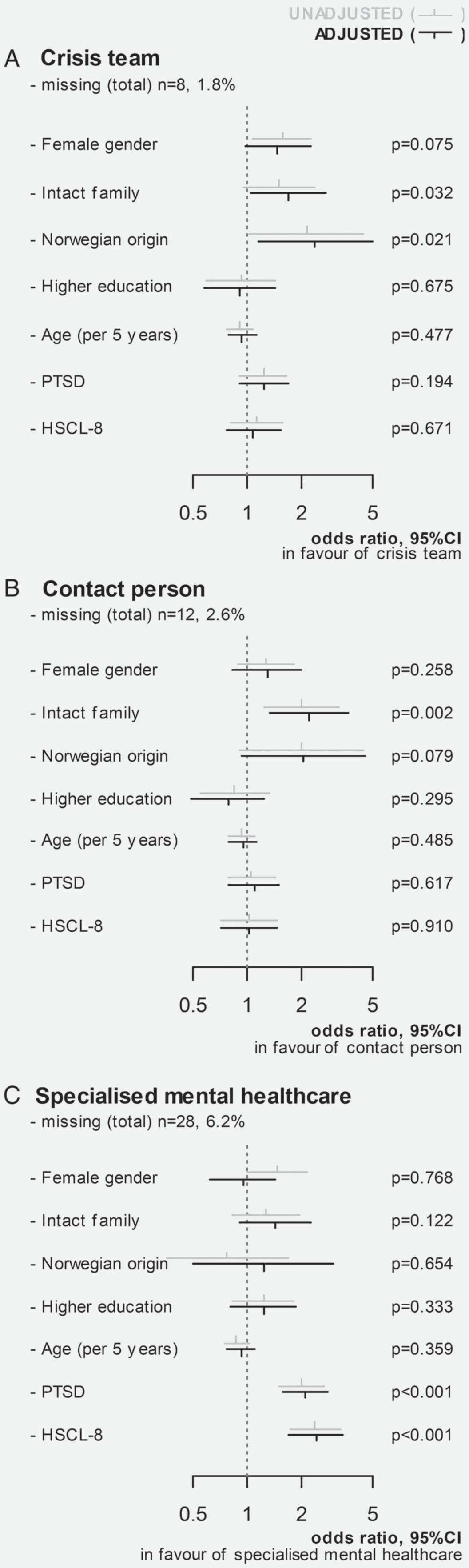

**Figure 1** Logistic regression models of proactive early outreach (crisis team (A), contact person (B) and specialised mental healthcare services (C)). Adjusted regressions include all independent variables of each model. As multicollinearity of PTSD-RI and HSCL-8 (r=0.82) is observed, the adjusted regressions of PTSD-RI and HSCL-8 are estimated without reciprocal adjustment to one another. The adjusted regressions of PTSD-RI and HSCL-8 thus include the sociodemographic variables of each model only. Adjusted regressions for the remaining variables of each model include the complete set of variables with both measures of psychopathology. All models are adjusted for clustering of members of the same families. p-values of the adjusted estimates are reported. Complete numbers are available in online supplementary table S3a–c.

minorities. Thus, our results suggest that families diverting from the norm may be susceptible to being left out of proactive crisis response.

Having a child seriously injured or threatened with violent death may be traumatising to parents. Inability of parents in coming to their child's rescue and the uncertainty awaiting news on their child may add to the trauma. Following the Utøya attack, high levels of PTSR, depression, and sick leave were observed. We speculate that the combination of indirect trauma victimhood of parents and the role as caregiver of a directly exposed victim may pose particular challenges to parents following a disaster, impacting negatively both on parental health and on their ability to provide care. In Norway, a life-time prevalence of PTSD of 2.6% has previously been reported in a sample of 2794 Norwegian adult twins.[25] Although the sample may not be considered representative of the Norwegian adult population, the findings are largely consistent with overall European figures.[26] When compared to a concurrent population-based study of post-traumatic stress in the early aftermath of the attack,[27] our data suggest levels of PTSR several times higher among the parents of the Utøya survivors than in the general Norwegian population at the time. Bridging the gap between the needs of parents affected by trauma, on the one hand, and the healthcare services available to them, on the other hand, may thus be of essence both in promoting the health of the parents, and also in strengthening the self-care capabilities of the affected family. An increased awareness of potential barriers to outreach may prove critical to the success of future crisis responses.

The second aim of this study was to explore whether specialised MHS following the Utøya shooting were indeed provided to parents in need. Our data suggest that engagement with a contact person was associated with the use of a GP, the entry point of the Norwegian healthcare system, but not with specialised MHS. Specialised MHS were significantly associated with levels of PTSR and depression alone. Our results suggest that early outreach may have facilitated access to healthcare services, but that referrals to specialised MHS were reserved for parents in need of such care.

**Table 3** Parental distress and the use of healthcare services (percentages of total, n=435)

| | Healthcare services* | | |
|---|---|---|---|
| | **Yes** | **No** | **Total** |
| Distress† | | | |
| Yes | 115 (26.4%) | 36 (8.3%) | 151 (34.7%) |
| No | 146 (33.6%) | 138 (31.7%) | 284 (65.3%) |
| Total | 261 (60.0%) | 174 (40.0%) | 435 (100%) |

*General practitioner and/or specialised mental healthcare services.
†Psychological distress reactions above cut-offs of the UCLA PTSD-RI (partial or full) and/or HSCL-5 (≥2.0).

Potentially unmet healthcare needs were considered in parents reporting significant distress and no healthcare services. This figure must be interpreted cautiously, as the parents may indeed have enjoyed other healthcare services than those addressed in our study. Moreover, lack of distress does not disprove a need for healthcare services, as the parents may have presented other healthcare needs than those addressed in our study, including somatic healthcare needs, as well as needs unrelated to the terrorist attack. Additionally, early distress may have prompted utilisation of healthcare services at an early stage, even if the distress was no longer present at the time of data collection. The figure may thus include a number of parents having benefitted from timely healthcare services.

Our data suggest relatively low numbers of parents presenting with a combination of clinically significant distress and no healthcare services. However, provision of healthcare services is no guarantee of covering the needs in patients, as services may be of suboptimal quality. Still, our data may reflect success of the postdisaster healthcare response in reaching out to a majority of the parents. A qualitative study suggests that a number of parents presented non-healthcare-related needs following the attack, including follow-up from school, workplace, practical support and professional counselling.[28] Future studies would benefit from exploring both the long-term trajectories of health and the range of healthcare and non-healthcare related needs that may arise post disaster.

### Strengths and limitations

The Utøya attack unfolded in an otherwise deserted place, with a fairly homogenous exposure, within a limited spatiotemporal frame and with a fixed population of young individuals. The aftermath of the attack allowed for complete identification of all survivors of the attack and with few constraints to immediate evacuation to appropriate healthcare facilities. The nature of the exposure, the ordered aftermath, and the perfect separation of parents and survivors add validity to our model of indirect exposure to terrorism. Moreover, we were able to recruit a high number of caregivers, including multiple caregivers of the majority of the survivors, and a high number of paternal caregivers. The parent sample thus enables a detailed understanding of the individual family structures; however, the full size of the parent population remains unknown.

In many cases of terror and natural disaster, victims and their families may be hard to identify. In the case of Utøya, the survivors were all identified by the police when rescued from the island. Moreover, prior to the terror attack, most Norwegian municipalities had already established functional crisis teams dealing with smaller scale events such as families bereaved from suicide, car accidents and sudden deaths. The municipalities thus had both infrastructure and experience in reaching out proactively to families. Nevertheless, as our figures represent the combined picture of crisis responses of n=128 municipalities, the outreach is likely to have varied across the country. Thus, the data reflect the overall national strategy of proactive early outreach, rather than experiences from a single adaptation of such a strategy.

The two measures of proactive outreach, crisis team and contact person, were established independently of one another and served distinct aims. Nevertheless, overlap of personnel between the measures may have occurred. The number or length of contacts with the crisis team is not known. Contact persons were to have a minimum of three contacts during the first year. More information regarding the nature and extent of the contact between families and outreach services would have been preferable. The interview covered a wide range of variables, and we had to limit the interview length in this early phase postdisaster. The context of this study is a universal and publicly funded healthcare system. The results may thus be most applicable in the context of similar healthcare systems.

The quality of data collected was good with respect to high overall response rates and low levels of missing data. Although a majority of the data was collected in face-to-face interviews with experienced clinicians, all data represent self-reports by the patients. No adjustments to variation in mode or time of data collection were made. All analyses are correlational. No causality can be demonstrated. We made no evaluation of the contents of the contacts with the healthcare services, treatment efficacy or quality of life.

## CONCLUSION

Following the Utøya terrorist attack, healthcare services were offered to parents presenting with elevated levels of distress. Still, our data suggest that healthcare needs in a number of parents presenting with high levels of distress were not met. Outreach strategies may be helpful in identifying healthcare needs and in facilitating access to healthcare services following a disaster. This study shows that particular attention to the complexity of family structures and ethnic diversity is critical in reaching out to modern families.

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**Contributors** GD and ST had the original idea for the study and developed the study design with LES, TW-L and JMH. GD, ST, LES and JMH interviewed participants. TW-L and JMH carried out the quantitative analyses. JMH wrote the first draft of the paper. All authors contributed to further drafts. JMH is the guarantor.

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**Competing interests** None declared.

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## SUPPLEMENTARY DATA:

*Supplementary Table 1 - Overview of parent participants versus parent non-participants.*

| | OR[a] | $\chi^2$ p-value |
|---|---|---|
| Participation of offspring | 91.1 | <0.001 |
| Cohabitation with participating offspring | 3.8 | <0.001 |
| Female gender of participating offspring | 1.04 | 0.874 |
| Norwegian origin | 3.74 | <0.001 |
| Labor Party affiliation | 8.22 | <0.001 |
| Geographic residence | [b] | 0.603 |

[a] odds ratio in favor of parental participation

[b] $\chi^2$ of five regions

*Supplementary table 2 – Overview of parent participants in respect to mode of participation (n=448-451).*

| | Mode of participation | | | | |
|---|---|---|---|---|---|
| | interview | questionnaire child ≥1992[a] | p-value[b] | questionnaire child <1992[c] | p-value[b] |
| *Dichotomous variables (number; %)* | | | | | |
| *All parents* | 309 (68.5%) | 43 (9.5%) | | 99 (22%) | |
| *Mothers* | 187 (73.0%) | 16 (6.3%) | 0.007 | 53 (20.7%) | 0.018 |
| *Fathers* | 122 (62.6%) | 27 (13.8%) | | 46 (23.6%) | |
| *Parent of intact family* | 204 (73.9%) | 7 (2.5%) | <0.001 | 65 (23.6%) | 0.960 |
| *Parent of other family* | 105 (60.0%) | 36 (20.6%) | | 34 (19.4%) | |
| *Norwegian origin* | 281 (68.4%) | 38 (9.2%) | 0.469 | 92 (22.4%) | 0.515 |
| *Non-Norwegian origin* | 26 (70.3%) | 5 (13.5%) | | 6 (16.2%) | |
| *Higher education* | 178 (68.5%) | 19 (7.3%) | 0.085 | 63 (24.2%) | 0.312 |
| *No higher education* | 129 (68.6%) | 24 (12.8%) | | 35 (18.6%) | |
| *Continuous variables (mean)* | | | | | |
| *Age* | 46.9 | 48.8 | 0.098 | 52.2 | <0.001 |
| *PTSD - range 0-4* | 1.15 | 1.11 | 0.741 | 1.06 | 0.282 |
| *HSCL-8 - range 1-4* | 1.71 | 1.58 | 0.169 | 1.67 | 0.575 |

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[a] Questionnaire, parent of child born in 1992 or later, due to unavailability to participate in a face-to-face interview.
[b] Unadjusted, logistic regression, questionnaire vs. interview
[c] Questionnaire, parent of child born in 1991 or earlier, selection by study design.

*Supplementary Table 3 - Logistic regression models of proactive early outreach (crisis team - A, and contact person - B) and specialized mental healthcare services - C, corresponding to Figure 1 a-c.*

**Model A – crisis team (n=445)**

| | **unadjusted regression** | | | **adjusted model** | | |
|---|---|---|---|---|---|---|
| | OR | 95% CI | p-value | OR | 95% CI | p-value |
| Female gender | 1.56 | 1.08-2.28 | 0.019 | 1.47 | 0.96-2.24 | 0.075 |
| Intact family | 1.50 | 0.94-2.37 | 0.086 | 1.69 | 1.05-2.72 | 0.032 |
| Norwegian origin | 2.12 | 1.03-4.36 | 0.041 | 2.39 | 1.14-4.98 | 0.021 |
| Higher education | 0.92 | 0.59-1.44 | 0.716 | 0.91 | 0.57-1.44 | 0.675 |
| Age (per 5 years) | 0.91 | 0.77-1.08 | 0.270 | 0.94 | 0.78-1.12 | 0.477 |
| PTSD RI | 1.23 | 0.91-1.65 | 0.175 | 1.24 | 0.90-1.71 | 0.194 |
| HSCL-8 | 1.12 | 0.80-1.56 | 0.503 | 1.08 | 0.76-1.54 | 0.671 |

**Model B – contact person (n=441)**

| | **unadjusted regression** | | | **adjusted model** | | |
|---|---|---|---|---|---|---|
| | OR | 95% CI | p-value | OR | 95% CI | p-value |
| Female gender | 1.27 | 0.89-1.83 | 0.189 | 1.29 | 0.83-2.00 | 0.258 |
| Intact family | 1.99 | 1.23-3.21 | 0.005 | 2.21 | 1.32-3.68 | 0.002 |
| Norwegian origin | 1.98 | 0.90-4.37 | 0.091 | 2.04 | 0.92-4.50 | 0.079 |
| Higher education | 0.85 | 0.54-1.32 | 0.460 | 0.78 | 0.49-1.25 | 0.295 |
| Age (per 5 years) | 0.93 | 0.79-1.10 | 0.387 | 0.94 | 0.78-1.12 | 0.485 |
| PTSD RI | 1.05 | 0.78-1.43 | 0.735 | 1.09 | 0.79-1.50 | 0.617 |
| HSCL-8 | 1.02 | 0.71-1.45 | 0.928 | 1.02 | 0.71-1.47 | 0.910 |

**Model C – specialized mental healthcare (n=419)**

| | **unadjusted regression** | | | **adjusted model** | | |
|---|---|---|---|---|---|---|
| | OR | 95% CI | p-value | OR | 95% CI | p-value |
| Female gender | 1.46 | 1.00-2.12 | 0.051 | 0.94 | 0.61-1.44 | 0.768 |
| Intact family | 1.26 | 0.81-1.96 | 0.300 | 1.44 | 0.91-2.27 | 0.122 |
| Norwegian origin | 0.77 | 0.35-1.68 | 0.515 | 1.23 | 0.50-3.01 | 0.654 |
| Higher education | 1.22 | 0.82-1.83 | 0.325 | 1.23 | 0.81-1.86 | 0.333 |
| Age (per 5 years) | 0.87 | 0.74-1.02 | 0.090 | 0.92 | 0.77-1.10 | 0.359 |
| PTSD RI | 2.00 | 1.51-2.64 | <0.001 | 2.08 | 1.55-2.79 | <0.001 |
| HSCL-8 | 2.38 | 1.71-3.32 | <0.001 | 2.42 | 1.71-3.43 | <0.001 |

*Adjusted regressions include all independent variables of each model. As multicollinearity of PTSD RI and HSCL-8 (r=0.82) is observed, and the adjusted regressions of PTSD RI and HSCL-8 are estimated without reciprocal adjustment of one another. The adjusted regressions of PTSD RI and HSCL-8 thus include the socio-demographic variables of each model only. Adjusted regressions for the remaining variables of each model include the complete set of variables including both measures of psychopathology.*

# PAPER 2

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# Healthcare to parents of young terrorism survivors: a registry-based study in Norway

Jon Magnus Haga,[1,2] Siri Thoresen,[1] Lise Eilin Stene,[1] Tore Wentzel-Larsen,[1,3] Grete Dyb[1,2]

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[1]Norwegian Centre of Violence and Traumatic Stress Studies (NKVTS), Oslo, Norway
[2]Faculty of Medicine, Institute of Clinical Medicine, University of Oslo, Oslo, Norway
[3]Centre for Child and Adolescent Mental Health, Eastern and Southern Norway, Oslo, Norway

**Correspondence to**
Dr Jon Magnus Haga;
j.m.haga@medisin.uio.no

## ABSTRACT

**Objectives** To assess changes in parents' short-term and long-term primary and specialised healthcare consumption following a terrorist attack threatening the lives of their children.

**Design** Registry-based study comparing parental healthcare service consumption in the 3 years before and the 3 years after a terrorist attack.

**Setting** The aftermath of the Utøya terrorist attack. The regular, publicly funded, universal healthcare system in Norway. Parents learning of a terrorist attack on their adolescent and young adult children.

**Participants** Mothers (n=226) and fathers (n=141) of a total of 263 survivors of the Utøya terrorist attack (54.6% of all survivors 13–33 years, n=482).

**Main outcome measures** We report primary and specialised somatic and mental healthcare service consumption in the early (0–6 months) and delayed (>6–36 months) aftermath of the attack, both in terms of frequency of services consumed (assessed by age-adjusted negative binomial hurdle regression) and proportions of mothers and fathers provided for (mean semiannual values). The predisaster and postdisaster rates were compared by rate ratios (RRs), and 95% CI were generated through bootstrap replications.

**Results** Frequency of primary healthcare service consumption increased significantly in both mothers and fathers in the early aftermath of the attack (mothers: RR=1.97, 95% CI 1.76 to 2.23; fathers: RR=1.73, 95% CI 1.36 to 2.29) and remained significantly elevated throughout the delayed aftermath. In the specialised mental healthcare services, a significant increase in the frequency of service consumption was observed in mothers only (early: RR=7.00, 95% CI 3.86 to 19.02; delayed: RR=3.20, 95% CI 1.49 to 9.49). In specialised somatic healthcare, no significant change was found.

**Conclusion** Following terrorist attacks, healthcare providers must prepare for increased healthcare needs in survivors and their close family members, such as parents. Needs may present shortly after the attack and require long-term follow-up.

### Strengths and limitations of this study

- This study employs an objective measure on healthcare consumption before and after a terrorist attack.
- The context of the study is a public, accessible and well-developed healthcare system.
- High number of both mothers and fathers participated. However, the full size of the parent population remains unknown.
- Only services provided by healthcare professionals were included. Psychosocial support from other professionals was not included.

## INTRODUCTION

Life threat to a child may jeopardise parents' long-term health. Diagnostic and Statistical Manual of Mental Disorders fifth edition[1] recognises learning that a close family member is being threatened with death or serious injury as being a potentially traumatising event. In recent years, numerous terrorist attacks have targeted children, adolescents and young adults who are not with their parents, either at school or during their leisure time (eg, summer camp, night club, café, concert hall[2–7]). Despite widespread concern about the postdisaster health of terrorism survivors, their parents' postdisaster reactions, coping and needs have received little attention.

Adverse health effects from experiencing life threat to one's child have previously been addressed in parents of seriously ill children. Elevated levels of parental anxiety, depression and post-traumatic stress reactions have been reported both following acute[8,9] and chronic disease,[10,11] as well as in the wake of traffic accidents[12,13]. Likewise, in parents of sexually abused children[14,15] and in parents of young soldiers deployed to hostile environments,[16,17] substantial emotional distress have been shown to persist for years. Several population-based studies have addressed the emotional impact of terrorism on individuals physically distant from the site of a terrorist attack.[18–23] However, only one study has specifically addressed distress in parents who witnessed or learnt of a terrorist attack that threatened the lives of their own children.[2] This small study (n=20 mothers) reported parental distress at levels comparable to those of the young survivors themselves. Traumatisation has previously also been shown to be associated with somatic health complaints, including respiratory, gastrointestinal and cardiovascular disease.[24–26] A registry-based study of parents who learnt that their adolescent and young adult children were caught in a pub fire in the Netherlands in 2001 reported that the postdisaster incidence of cardiovascular health problems, as recorded by the primary healthcare provider, was significantly higher in parents of burnt survivors than in unaffected community controls.[27] Thus, although limited, current evidence suggests that terrorism may potentially elicit both mental and somatic healthcare needs in parents of survivors.

Our previous studies of the mothers and fathers of the Utøya survivors have demonstrated substantial and lasting levels of emotional distress.[28 29] The present study employs national registry-based healthcare data to assess the parents' primary and specialised healthcare consumption before and after the terrorist attack. Separately in mothers and fathers, we first investigated whether the frequency of parents' primary and specialised healthcare service consumption in the early (0–6 months) and delayed (>6–36 months) aftermath of the terrorist attack was higher than in the 3-year period before the terrorist attack. Second, we examined whether the semiannual proportions of mothers and fathers consuming one or more healthcare services were increased (early and delayed), when compared to predisaster levels. Third, we assessed the reasons for parents accessing healthcare services in the aftermath of the terrorist attack, by mapping out reasons for encountering the primary healthcare services, the entry point to the healthcare system in Norway.

## METHOD

### Setting

The setting of this study is the aftermath of the Utøya terrorist attack.

### Trauma

On 22 July 2011, two terrorist attacks shook Norway. A single perpetrator detonated a bomb in the government quarter in Oslo, before setting out on a shooting spree at the youth summer camp on Utøya Island less than 2 hours later. The youth were trapped on the small island with the perpetrator for more than 1 hour. The attack left 69 dead and 495 alive, of whom 35 had sustained severe physical injuries.[30] The parents, all physically distant from the island, watched events unfold via live media reports. Some parents had access to intermittent telecommunication with their offspring on the island. Following the attack, the survivors were reunited with their families throughout the country.

### Post-trauma care

Soon after the terrorist attack, an early proactive outreach programme was established, in line with the current trauma-informed consensus of expert opinions.[31] Multi-disciplinary crisis teams, established in affected municipalities (n=128), were to provide the immediate psychosocial support to those in need; dedicated contact persons were to proactively monitor and support the affected families throughout the first year postdisaster and to facilitate access to regular healthcare services as required.[28 32] Postdisaster healthcare services were provided by the regular two-level healthcare system in Norway:[33] level 1, including the primary healthcare services of general practitioners (GPs) and emergency primary healthcare, provides services for both somatic and mental health complaints and acts as the entry point and gatekeeper to secondary healthcare services; level 2, the secondary healthcare services, provides specialised mental and specialised somatic healthcare services and is accessed through medical referrals only. Regular healthcare services in Norway are publicly funded and accessible throughout the country.

### Design

This is a longitudinal, prospective study, assessing registry-based data on parental healthcare consumption in the periods 3 years before and after the terrorist attack (22 July 2008 to 21 July 2014).

### Procedure

Parental recruitment and participation in the earlier waves of the larger Utøya study have been explained in detail previously.[28 34] In summary, the earlier waves had open cohort designs, extending invitations to all eligible participants (parents of survivors 13–33 years, n=482). The third wave of the study, on which this paper reports, had a closed cohort design, meaning that only parents who had participated in either of the previous waves (n=532) were invited. Invitations to the third wave were distributed by mail at three years after the disaster and included information on how to opt out.

### Sample

Overall, 299 mothers and 233 fathers (n=532 parents) participated in at least one of the three waves of the Utøya study; 75.5% of the mothers (n=226) and 60.5% of the fathers (n=141) took part in wave 3. The participants represented 251 distinct families and cared for a total of 263 survivors (54.6% of all Utøya survivors aged 13–33 years). Mean ages of mothers and fathers at the time of the attack were 46.7 (SD 5.8) and 49.7 (SD 5.9) years, respectively. A majority of the parents were of Norwegian origin (n=335, 92.0%, missing n=3), held a university or a university college degree (n=225, 61.3%), had an average or above-average financial situation (n=297, 80.9%) and were, at the time of data collection, mostly employed (n=314, 86.3%, missing n=3). Attrition from previous waves (n=165, 31.0%) favoured male gender (OR 2.02, $\chi^2$ p<0.001). Neither non-Norwegian origin (OR: mothers=1.00, $\chi^2$ p=0.996; fathers=1.15, $\chi^2$ p=0.805) nor levels of early post-traumatic stress reactions (mean—mothers: 1.34 vs 1.34, Student's t-test p=0.967; fathers: 0.80 vs 0.88, Student's t-test p=0.358) were associated with non-participation at wave 3. Most participants consented to collection of registry-based data (mothers: n=222, 98.5%; fathers: n=136, 96.5%).

## Measures

*Primary healthcare consumption* was assessed through the Health Economics Administration (HELFO) database by analysing reimbursement claims filed by primary healthcare providers, GPs, to the national insurance scheme. All records dating from 22 July 2008 to 21 July 2014 were included, regardless of whether they referred to services provided at a GP clinic, during house calls, by telephone or mail, provided by regular GPs or locum GPs, within regular office hours or when on-call. A total of 13 419 records were identified, of which 42 (0.3%) were duplicates (matching date, time, diagnosis, provider and mode of contact). The non-duplicates (n=13 377) were subdivided according to the type and time of service (online supplementary table 1). Reason for encountering was recorded according to International Classification of Primary Care revised 2nd edition (ICPC-2)[35] and clustered according to type of health problem.[36]

*Specialised healthcare consumption* was assessed using the Norwegian Patient Registry (NPR)—activity reported by hospitals and hospital clinics—and the HELFO database—reimbursement claims filed to the National Insurance Scheme by private specialised healthcare providers. All services recorded by physicians and psychologists dating from 22 July 2008 to 21 July 2014 were included, irrespective of whether the service was provided in a public hospital, a private clinic, by telephone or mail and within regular office hours or not. A total of 6024 specialised healthcare services were identified (NPR n=4152 services, HELFO database n=1872), of which 193 (3.2%) were duplicates (matching date, diagnosis, healthcare provider and mode of contact). The services were subdivided into specialised mental healthcare services (n=2079) and specialised somatic healthcare services (n=3752) and, further, according to type and time of service (online supplementary table 1).

*Quality of data*: Claims to the national insurance scheme (HELFO) are submitted electronically. All claims with missing patient IDs are automatically rejected and returned to the healthcare provider for resubmission. Thus, the HELFO database contains no data with missing patient ID. In contrast, NPR does not reject incomplete information and consequently contains a small number of entries with missing patient ID (online supplementary table 2).

## Statistics

The data analysed in this paper are count data (ie, frequencies of occurrences within a predefined time period) that were recorded in the 3 years before and after a terrorist attack. Mothers and fathers were assessed separately throughout the paper.

Descriptive statistics are presented graphically. The distribution of overall frequencies by which healthcare services were accessed before and after the terrorist attack is presented as split violin diagrams.[37] Rates of healthcare service consumption across the study period and the proportions of individuals accessing healthcare services semiannually are presented by line and pie charts, in a second figure. As is often found in data on healthcare consumption,[38] our data were overdispersed (variance greater than the mean value) and exhibited excess zeros (individuals with no occurrences). Numerical values mirroring the graphics included in the paper are tabulated in the online supplementary material.

The statistical analyses included in this paper compare postdisaster with predisaster healthcare consumption. Parents' age was hypothesised to influence healthcare needs independently of the terrorist attack being investigated. Thus, rates of partents' predisaster and postdisaster healthcare consumption were predicted from age-adjusted regression models, rather than assessing the observed predisaster and postdisaster values directly. Negative binomial hurdle regressions were chosen for rate predictions, as this method is well suited for overdispersed count data exhibiting excess zeros.[39] In order for results to be interpreted in terms of rates, negative binomial hurdle regressions need to be offset for the observational period, also known as the person-time at risk. In our material, hospital admissions were considered to make an individual unavailable for healthcare services by other healthcare providers. Thus, in our study, observational periods were defined as days of non-hospitalisation within each time period being investigated. Negative binominal hurdle regression is a two-component regression model.[39] Thus, model predictions need to be calculated for a predefined index individual. In our study, the index parent was defined as a mother or a father of 47 years of age at the time of the attack, reflecting the median age of the full parent sample. We chose to make predictions for the same age in both mothers and fathers, despite the father sample being slightly older than the mother sample, in order to increase comparability.

The detailed statistical procedure was as follows. First, predictions of frequency of healthcare service consumption were made for each period of interest, that is, predisaster and the early and delayed aftermath. Second, annualised rates of healthcare service consumption were obtained by dividing predicted frequencies by the duration of the time period investigated (ie, before=36 months, early aftermath=6 months, delayed aftermath=30 months). Additionally, the proportion of mothers and fathers acquiring services within a 6-month period was calculated by averaging observed semiannual proportions (by design, the frequency of non-zero predictions equals the observed value in negative binomial hurdle regressions). Finally, postdisaster versus predisaster rate ratios (RRs) were computed by dividing the rates of early and delayed postdisaster healthcare consumption (both the frequency of service consumption and the proportion of individuals accessing services) by the corresponding predisaster rates. Bias-corrected and accelerated 95% CI of RR were generated through bootstraps of 10 000 replications.

All analyses were made using the full dataset, which included *all services* provided by primary and specialised healthcare service providers. As supplementary material, the analyses were repeated on a dataset including only *in person* consultations with the healthcare provider (ie, excluding the telephone consultations, mail correspondence, etc).

Across the time period investigated, improved quality of reporting practices to NPR was observed (fewer entries were recorded with missing patient IDs, online supplementary table 2). The improved quality of reporting practices was most evident between 2009 and 2010. In the final year predisaster, levels of missing patient IDs were not substantially different to postdisaster levels. As incomplete entries in NPR may have resulted in an underestimation of pre-disaster healthcare consumption, sensitivity analyses were performed by repeating all analyses that included the 3-year predisaster NPR data, with NPR data from the final year predisaster only.

Analyses were performed with R V.3.0.3 (R Foundation for Statistical Computing), with the R-packages *pscl* (1.4.9) for hurdle regressions and *boot* (1.3–13) for bootstrap analyses. Violin plots were generated through an adaptation of the *vioplot* (0.2) package.

## RESULTS

The overall aim of this study was to create a detailed description of predisaster and postdisaster patterns of parental healthcare consumption. Thus, we began by mapping out the frequency distributions by which each parent accessed healthcare services in the periods 3 years before and after the attack (figure 1A,B). Notably, in primary healthcare, nearly all parents were found to have accessed healthcare services on one or more occasion both predisaster and postdisaster. In the specialised mental healthcare services, only a minority of the parents had received services. High variability in frequency of acquisition was found for both services.

Figure 2A,B descriptively outlines the trajectories of healthcare consumption over time. Upper halves of figures (line charts) report the annual rates at which healthcare services were provided to the parents before and after the attack. Bottom halves of figures (pie charts) report the numbers and proportion of parents provided for within each 6-month period. Notably, in the early aftermath of the attack, we observed a sharp increase in frequency of both primary and specialised mental healthcare services acquired. In the delayed aftermath, the observed frequency of healthcare service acquisition largely levelled out.

Figure 3A,B presents the output of the statistical analyses comparing predisaster and postdisaster healthcare consumption. The horizontal axes indicate the RR of postdisaster versus predisaster healthcare consumption. The dotted vertical line indicates no difference (RR=1). A statistically significant difference is indicated when the 95% CI does not overlap this line. First, rates of healthcare *services* used (figure 3A) before and after the attack were addressed. We found that age-adjusted predictions of primary healthcare service consumption rates in mothers and fathers were significantly elevated both in the early and delayed aftermath, when compared with the 3-year period before the terrorist attack. Similarly, in mothers, but not in fathers, a significant increase in rates of postdisaster specialised mental healthcare service consumption was demonstrated, both in the early and delayed aftermath. In fathers, specialised mental healthcare service consumption could not be reliably bootstrapped, due to an insufficient number of occurrences. No significant increase in rates was found in the specialised somatic healthcare services. Second, we compared the proportion of *individuals using the services* (figure 3B) before and after the attack. We found that, compared with predisaster values, significantly more mothers and fathers used primary healthcare services, both in the early and delayed aftermath. Furthermore, significantly more mothers and fathers used specialised mental healthcare services in the early aftermath, when compared with predisaster levels. In the delayed aftermath, the numbers of mothers, but not fathers, using the specialised mental healthcare services remained significantly elevated. Sensitivity analyses addressing the improved reporting practices to NPR across the study period consistently returned conclusions that were not appreciably different to the findings presented in this paper and are not shown.

Finally, we assessed the reasons for parents encountering the healthcare services in the aftermath of the attack, as recorded by the primary healthcare providers at the time of the services' provision (figure 4). Notably, psychological health complaints dominated reasons for encountering in both genders. In fact, 78.4% of mothers (n=174) and 47.1% of fathers (n=64) consulted their GP about psychological complaints (ICPC-2, chapter 'P') in the aftermath of the attack. More than one-third were diagnosed with depression (mothers: n=42, 19.0%; fathers: n=15, 11.0%) or post-traumatic stress disorder (PTSD) (mothers: n=14, 6.3%; fathers: n=10, 7.4%) or both (mothers: n=9, 4.1%; fathers: n=4, 2.9%). Individuals with psychological health complaints were largely managed by primary healthcare services without receiving specialised mental healthcare services (mothers: n=106, 60.9%; fathers: n=47, 73.4%).

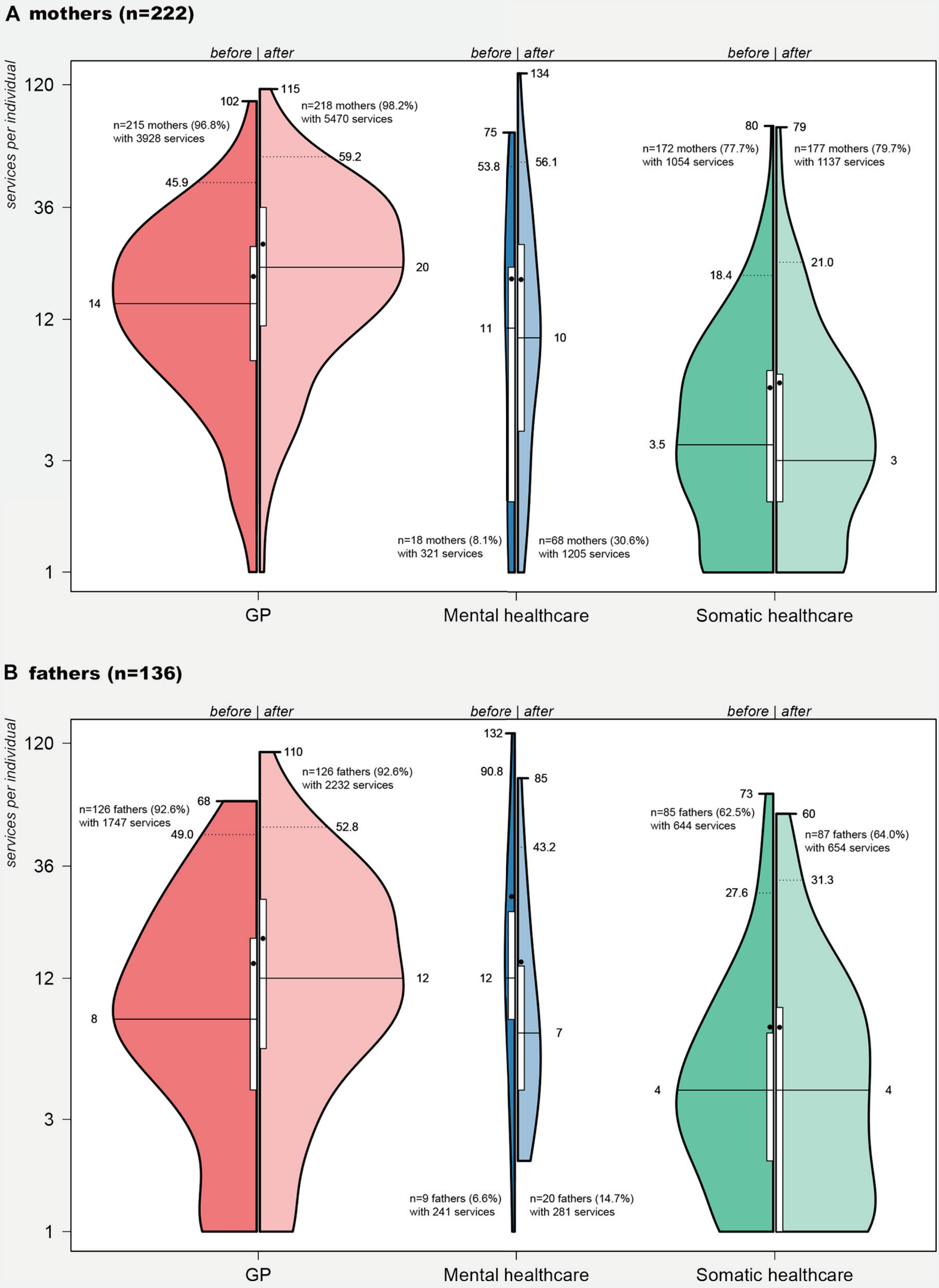

**Figure 1** (A and B) Split-violin diagrams presenting frequency distributions of parents' overall healthcare service consumption before (left violins) and after (right violins) the terrorist attack. The vertical axes indicate the frequency by which the healthcare services were used. Each curve represents a Kernel density estimation, in which the area under curves reflect the proportion of mothers and fathers accessing the services. White vertical box: interquartile range (Q1–Q3). Black bullet: mean value. Solid horizontal line: median value. Dotted horizontal line: 95th percentile. Upper edge: maximum value.

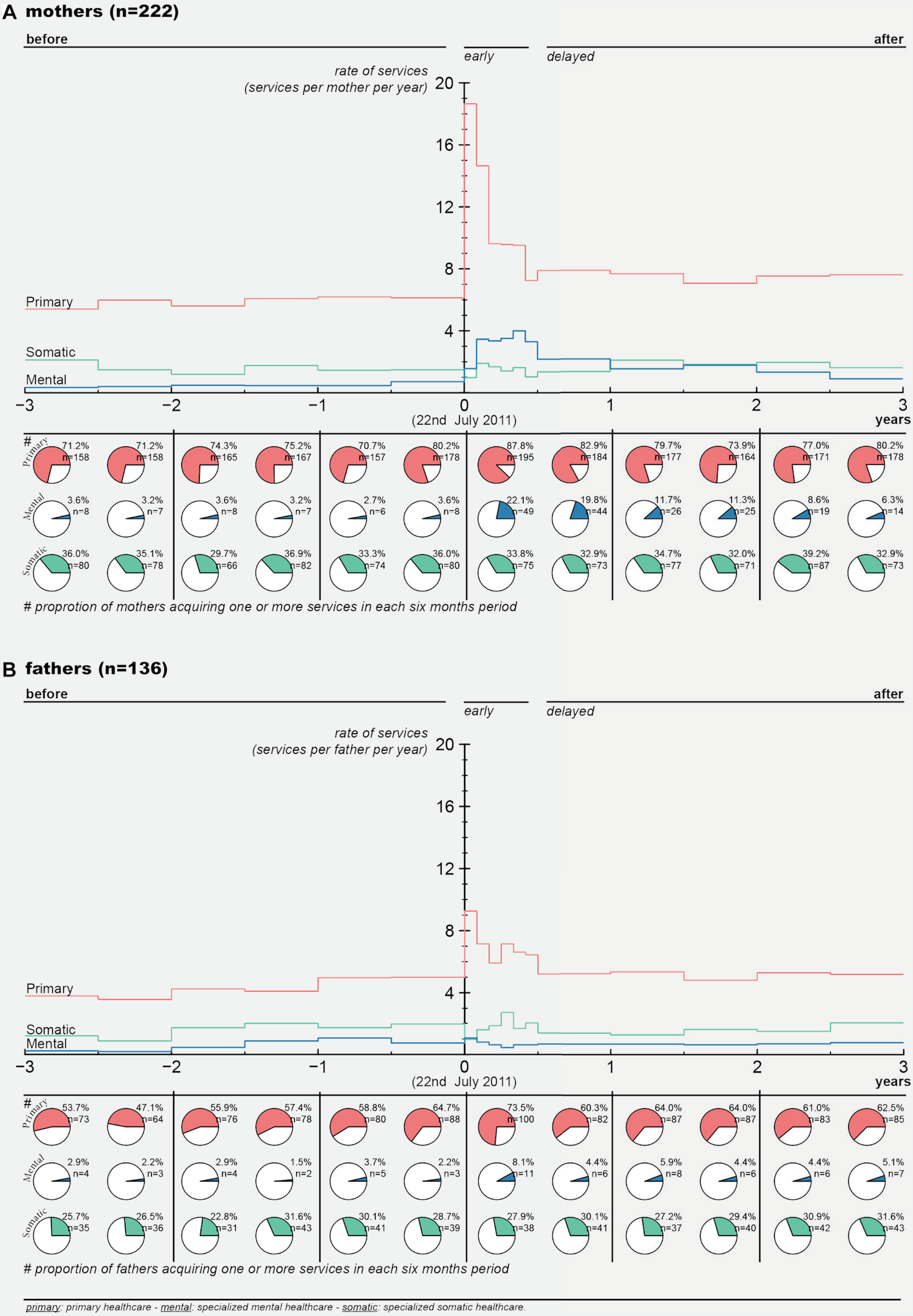

**Figure 2** (A and B) Healthcare service consumption across time, presented as rates of services used (line chart) and proportions of mothers and fathers provided for within each 6-month period (pie chart). Corresponding numeric values and values for *in person* consultations only are available in online supplementary table 3.

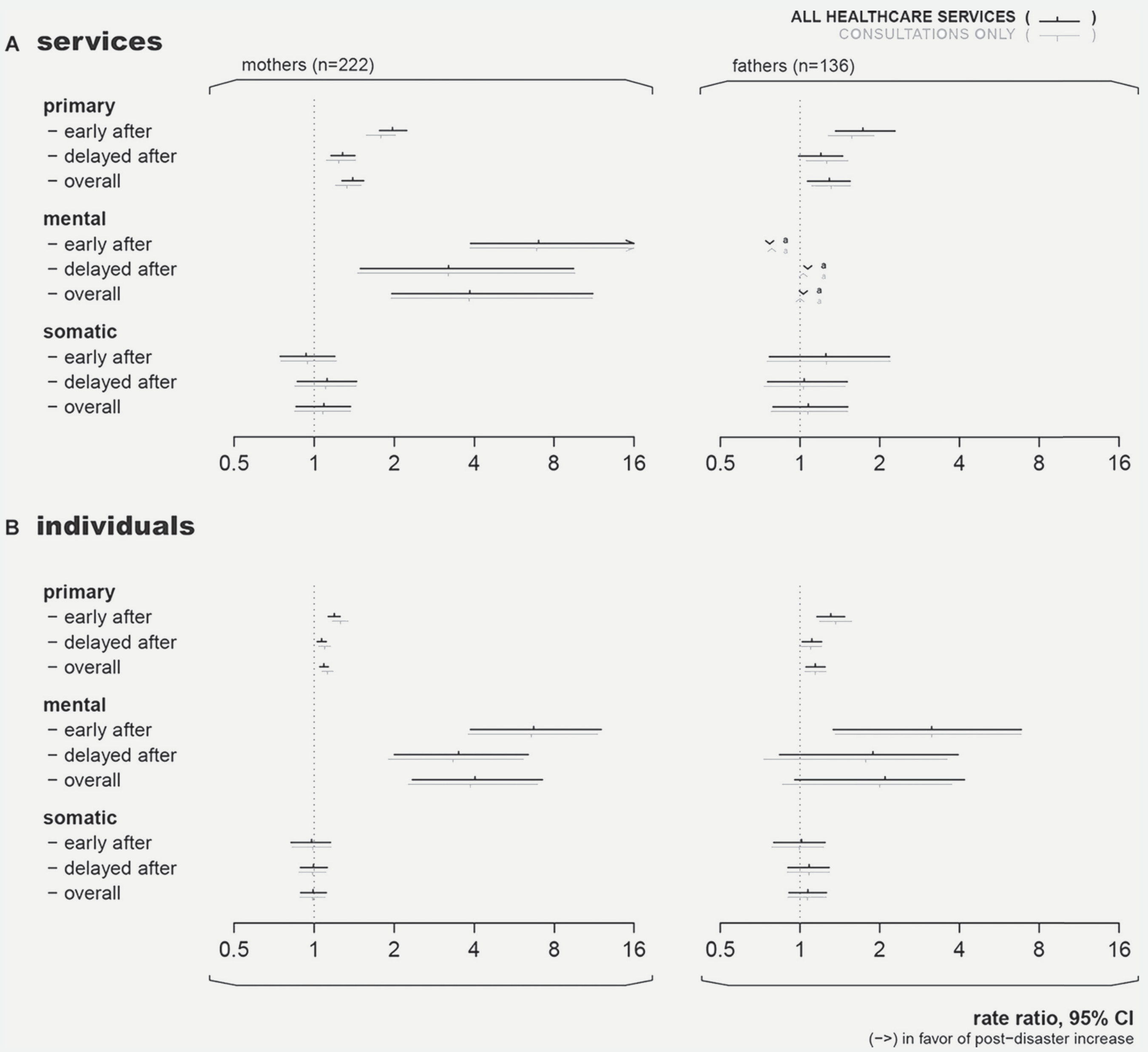

**Figure 3** Rate ratios of parents' postdisaster versus predisaster healthcare consumption, in terms of (A) predicted frequency of healthcare service consumption (age-adjusted negative binomial hurdle regressions) and (B) observed proportions of individuals provided for (mean semiannual values). 95% CIs of the ratios were generated through bootstrap replications. Corresponding numerical values are available in online supplementary table 4. $^{a}$ indicates that ratio of estimates could not be reliably bootstrapped.

## DISCUSSION

The overall aim of this study was to make a detailed description of predisaster and postdisaster healthcare consumption in parents of the Utøya terrorist attack survivors. We found that primary healthcare was the larger provider of healthcare services both before and after the terrorist attack. The number of services provided to both mothers and fathers increased soon after the terrorist attack and peaked within the first 6-month period. The increase in primary healthcare services both in the early and delayed aftermath was largely attributable to psychological health complaints, as recorded by their primary healthcare provider. In Norway, primary healthcare is the entry point to specialised healthcare, as well as to social benefits and public welfare services. Our figures suggest an important role for GPs in managing parents' postdisaster distress. GPs need to be aware that high numbers of parents may turn to primary healthcare with psychological health complaint in the wake of a terrorist attack, enabling appropriate preparations.

Increase in postdisaster primary healthcare consumption was most notable in female participants. Previous research has identified female survivors of trauma as more susceptible to developing PTSD than men.[40 41] Thus, our data may in part reflect gender differences in postdisaster stress reactions. However, an alternative explanation

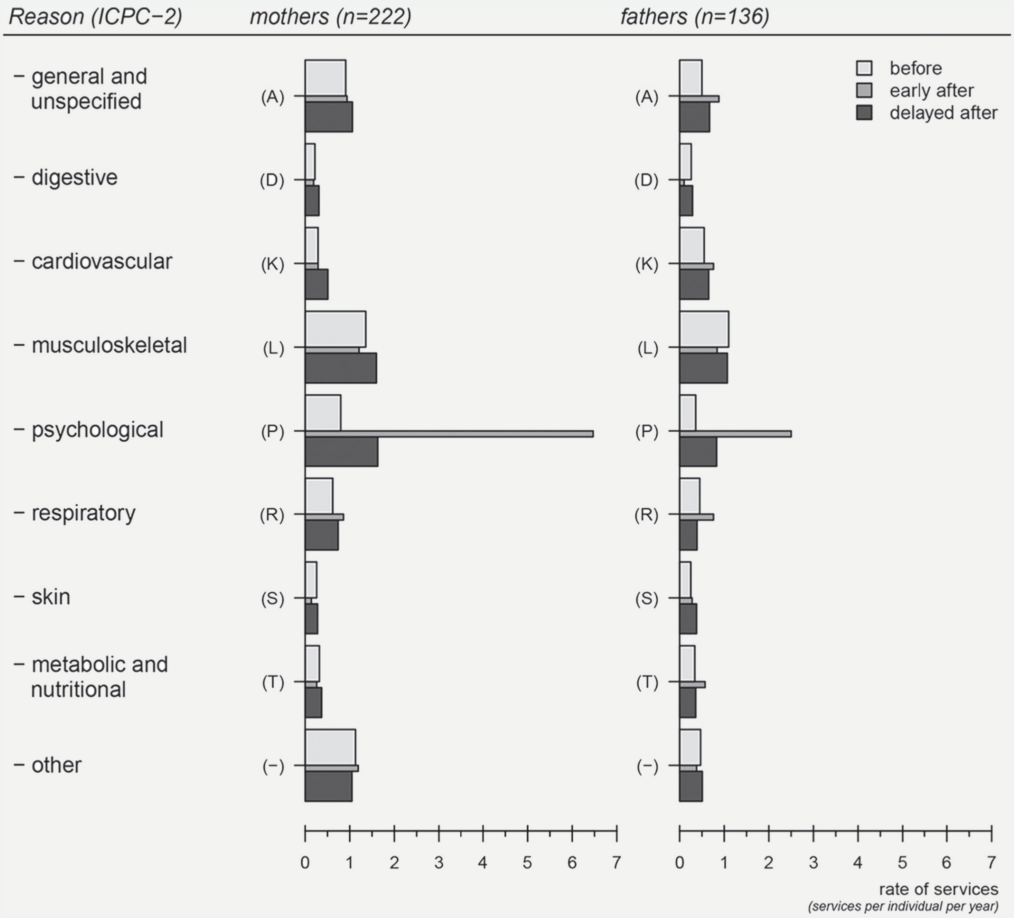

**Figure 4** Reasons for accessing the primary healthcare services, according to ICPC-2, in the 3-year period before and after the terrorist attack. Categories with incidence of <0.2 services per person per year are pooled ('other'). Widths of bars correspond to duration of time interval. Total number of services: 13 337. Corresponding numeric values are available in online supplementary table 5. ICP-2, International Classification of Primary Care revised 2nd edition.

is that distressed fathers may have been more reluctant than mothers to seek help for mental health complaints, as has been suggested by previous research.[42 43] Potential barriers to accessing postdisaster healthcare in men and women should be further addressed in future research.

A significant increase in numbers of both mothers and fathers accessing specialised mental healthcare services was found in the current study. This finding is in line with our previous work, demonstrating significant associations between the parents' post-traumatic stress reactions and their self-reported specialised healthcare consumption in the early aftermath of the terrorist attack.[28] Lack of capacity or capability of the primary healthcare services in providing for traumatised patients, including lack of appropriate experience or expertise, may have contributed to early referrals to the specialised healthcare services in some patients. However, in keeping with a registry-based study of the psychiatric diagnoses assigned by Swedish specialised mental healthcare providers to survivors of the 2004 Southeast Asian Tsunami,[44] the increase in specialised mental healthcare consumption is likely largely to include the most severely traumatised parents—those in need of specialised mental healthcare interventions.

In the aftermath of disaster, an increase in healthcare consumption may result from both new patients entering the healthcare system and an increase in frequency of service consumption among those already in the services.[45] In our study, most participants were found to use primary healthcare services both before and after the terrorist attack. Thus, the increased primary healthcare service consumption stemmed largely from an increase in frequency of healthcare consumption in individuals that were already known to the services. In contrast, the specialised mental healthcare services faced an influx of patients that were largely new to the services. Potential differences in patterns of parents' postdisaster healthcare consumption according to disaster characteristics, including disaster magnitude, duration and potential for damage, whether it being a natural or a man-made disaster, whether it being a shared or a non-shared trauma of parent and child, and postdisaster access to psychosocial services, are still largely to be investigated.

## Strengths and limitations

The context of this study is a universal, public, accessible and well-developed healthcare system. The study employs an objective measure on healthcare consumption, recorded by the healthcare provider at the time of the healthcare service provision. The study allows for reliable comparison of predisaster and postdisaster data, with negligible levels of missing data. Nonetheless, observed healthcare consumption does not objectively reflect the healthcare needs. Consumption may represent a combination of the perception of needs of a patient deciding to seek medical advice and the clinical judgement of a provider, who, for example, may encourage renewed contacts, make referrals, among others. Although most applicable in similar clinical settings, we hold that our findings may reflect underlying postdisaster distress and thereby healthcare needs that may arise in parents anywhere in the world, in the face of terror. Whether similar patterns of healthcare needs arise in parents after other types of shared or non-shared traumatic exposures, such as when a child is struck by a natural disaster, traffic accident or serious illness, remains to be investigated.

The current study reports healthcare services provided by healthcare professionals only. Thus, parts of the postdisaster outreach programme were not included.[28] In the aftermath of a terrorist attack, many countries are likely to adopt some kind of crisis response, as was reported following the major terrorist attacks in France[46] and the UK.[47] The organisation and contents of such programmes vary across different country settings.[48] Following the Utøya terrorist attack, a majority of the mothers and fathers were contacted by proactive outreach services in their municipalities.[28] Psychosocial support through postdisaster outreach may facilitate access to regular healthcare services and thus potentially increase overall healthcare consumption. On the other hand, it may also alleviate early health complaints and thus reduce consumption. The contents of the psychosocial services provided to parents are not known in detail. No adjustment for engagement with the outreach programme was made. Finally, although uncommon due to universal coverage of the national insurance scheme, some participants may have self-financed access to additional healthcare services or obtained services abroad.

## CONCLUSION

Widespread healthcare needs have previously been reported among survivors of terrorist attacks.[49] Our study emphasises the importance of thinking about survivors in a broader, more systemic way. Postdisaster increase in healthcare needs may not be limited to individuals rescued from the site of a terrorist attack, but may also include close family members, such as parents.

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**Contributors** JMH, ST, LES and GD conceived of the study and developed the study design with TW-L. JMH, LES and GD gathered the data. JMH and TW-L conducted the statistical analyses. JMH wrote the first draft of the paper. All authors contributed to further drafts and approved the final submission, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. JMH is the guarantor of the manuscript being an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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**Competing interests** All authors have completed the International Committee of Medical Journal Editors uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: the study was supported by the Norwegian Directorate of Health; JMH and LES have received research grants from the Norwegian Research Council; no other relationships or activities that could appear to have influenced the submitted work. All researchers worked independently from funders.

**Patient consent** Obtained.

**Ethics approval** Consents to participation and collection of registry-based data were obtained in writing from all participants. The study was approved by the Regional Committees for Medical and Health Research Ethics in Norway.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Data supporting the findings of this study are not publicly available. The patient-level, registry-based data may be accessed through the Norwegian Directorate of Health (https://helsedirektoratet.no/english). Restrictions apply. Technical appendix and statistical code are available from the corresponding author.

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***Supplementary table 1*** – Nature of the different healthcare services provided to the study participants in the three year periods before and after the Utøya attack (total number of services: 19,208).

| | Primary healthcare | | Specialized mental healthcare | | Specialized somatic healthcare | |
|---|---|---|---|---|---|---|
| | before (n=5,675) | after (n=7,702) | before (n=578) | after (n=1,501) | before (n=1,836) | after (n=1,916) |
| outpatient, consultations | 3130 (55.2) | 4082 (53.0) | 531 (91.9) | 1374 (91.5) | 1631 (88.8) | 1694 (88.4) |
| outpatient, other services[a] | 2545 (44.8) | 3620 (47.0) | 31 (5.4) | 112 (7.5) | 67 (3.6) | 97 (5.1) |
| inpatient, admissions[b] | - | - | 16 (2.8) | 15 (1.0) | 138 (7.5) | 125 (6.5) |

[a] telephone consultations, mail correspondence etc.

[b] mean duration of admissions, pre- and post-disaster - specialized mental healthcare – 10.7 days (SD 9.2) and 15.1 days (SD 17.2) - specialized somatic healthcare - 5.4 days (SD 7.6) and 4.60 days (SD 6.9).

***Supplementary table 2*** – Incomplete entries (missing patient ID) in the Norwegian Patient Registry[1]

a) Specialized mental healthcare services

| year | missing ID (%) |
|---|---|
| 2008 | 5.80 % |
| 2009 | 4.79 % |
| 2010 | 0.78 % |
| 2011 | 0.49 % |
| 2012 | 0.53 % |
| 2013 | 0.30 % |
| 2014 | 0.25 % |

b) Specialized somatic healthcare services

| year | missing ID (%) |
|---|---|
| 2008 | 4.89 % |
| 2009 | 3.31 % |
| 2010 | 2.19 % |
| 2011 | 2.18 % |
| 2012 | 1.66 % |
| 2013 | 1.32 % |
| 2014 | 1.22 % |

[1] Source: the Norwegian Patient Registry.

***Supplementary table 3*** – Observed rates of healthcare service consumption in the three-year periods before and after the terrorist attack, annualized values. Supplement to Figure 2.

| | mothers (n=222) | | | Fathers (n=136) | | |
|---|---|---|---|---|---|---|
| | primary | mental | somatic | primary | mental | somatic |
| **Before** (all services \| consultations only) | | | | | | |
| 2008-Jul-22 to 2009-Jan-21 | 5.41 \| 3.33 | 0.34 \| 0.34 | 2.12 \| 2.05 | 3.79 \| 2.24 | 0.24 \| 0.22 | 1.21 \| 1.16 |
| 2009-Jan-22 to 2009-Jul-21 | 5.98 \| 3.05 | 0.41 \| 0.39 | 1.49 \| 1.46 | 3.57 \| 1.93 | 0.19 \| 0.19 | 0.87 \| 0.72 |
| 2009-Jul-22 to 2010-Jan-21 | 5.60 \| 3.13 | 0.49 \| 0.48 | 1.19 \| 1.17 | 4.25 \| 2.35 | 0.46 \| 0.34 | 1.72 \| 1.69 |
| 2010-Jan-22 to 2010-Jul-21 | 6.08 \| 3.14 | 0.47 \| 0.44 | 1.76 \| 1.64 | 4.10 \| 2.46 | 0.87 \| 0.87 | 2.00 \| 1.97 |
| 2010-Jul-22 to 2011-Jan-21 | 6.19 \| 3.35 | 0.47 \| 0.43 | 1.46 \| 1.38 | 4.97 \| 2.91 | 1.06 \| 1.04 | 1.72 \| 1.66 |
| 2011-Jan-22 to 2011-Jul-21 | 6.13 \| 3.17 | 0.72 \| 0.64 | 1.49 \| 1.40 | 5.00 \| 2.85 | 0.74 \| 0.71 | 1.96 \| 1.94 |
| **After** (all services \| consultations only)<br>*early aftermath* | | | | | | |
| 2011-Jul-22 to 2011-Aug-21 | 18.65 \| 7.62 | 1.57 \| 1.35 | 0.97 \| 0.97 | 9.26 \| 4.59 | 1.06 \| 0.97 | 0.97 \| 0.97 |
| 2011-Aug-22 to 2011-Sep-21 | 14.65 \| 7.57 | 3.46 \| 3.03 | 1.89 \| 1.84 | 7.15 \| 3.88 | 0.79 \| 0.79 | 1.59 \| 1.50 |
| 2011-Sep-22 to 2011-Oct-21 | 9.62 \| 4.92 | 3.35 \| 3.19 | 1.68 \| 1.62 | 5.91 \| 3.09 | 0.62 \| 0.62 | 1.85 \| 1.85 |
| 2011-Oct-22 to 2011-Nov-21 | 9.57 \| 5.19 | 3.51 \| 3.30 | 1.41 \| 1.41 | 7.15 \| 3.88 | 0.44 \| 0.44 | 2.74 \| 2.74 |
| 2011-Nov-22 to 2011-Dec-21 | 9.51 \| 5.03 | 4.00 \| 3.78 | 1.62 \| 1.62 | 6.62 \| 3.26 | 0.62 \| 0.62 | 1.68 \| 1.68 |
| 2011-Dec-22 to 2012-Jan-21 | 7.24 \| 3.68 | 3.30 \| 2.97 | 1.03 \| 0.86 | 6.44 \| 3.79 | 0.62 \| 0.62 | 2.03 \| 1.85 |
| *delayed aftermath* | | | | | | |
| 2012-Jan-22 to 2012-Jul-21 | 7.89 \| 3.86 | 2.17 \| 1.95 | 1.35 \| 1.32 | 5.21 \| 3.00 | 0.68 \| 0.63 | 1.38 \| 1.29 |
| 2012-Jul-22 to 2013-Jan-21 | 7.67 \| 4.25 | 1.53 \| 1.43 | 2.09 \| 2.01 | 5.32 \| 3.31 | 0.68 \| 0.63 | 1.26 \| 1.22 |
| 2013-Jan-22 to 2013-Jul-21 | 7.05 \| 3.64 | 1.76 \| 1.68 | 1.82 \| 1.71 | 4.78 \| 2.72 | 0.63 \| 0.53 | 1.62 \| 1.51 |
| 2013-Jul-22 to 2014-Jan-21 | 7.52 \| 4.10 | 1.32 \| 1.24 | 1.95 \| 1.86 | 5.26 \| 3.04 | 0.69 \| 0.59 | 1.50 \| 1.38 |
| 2014-Jan-22 to 2014-Jul-21 | 7.60 \| 3.80 | 0.88 \| 0.83 | 1.6 \| 1.43 | 5.16 \| 2.87 | 0.76 \| 0.71 | 2.04 \| 1.87 |
| **Summary** (all services \| consultations only) | | | | | | |
| Average before | 5.90 \| 3.20 | 0.48 \| 0.45 | 1.58 \| 1.52 | 4.28 \| 2.46 | 0.59 \| 0.56 | 1.58 \| 1.52 |
| Average after | 8.21 \| 4.22 | 1.81 \| 1.68 | 1.71 \| 1.62 | 5.47 \| 3.12 | 0.69 \| 0.63 | 1.60 \| 1.51 |

primary: primary healthcare, mental: specialized mental healthcare, somatic: specialized somatic healthcare

***Supplementary table 4*** – Rate ratios of parents' post- versus pre-disaster healthcare consumption, in terms of (a) predictions of frequency of healthcare service consumption (age-adjusted negative binomial hurdle regression) and (b) proportions of individuals provided for (mean semiannual values). Confidence intervals (95%) of the rate ratios were generated through bootstrap replications. Supplement to Figure 3.

| | | | mothers (n=222) | | | | fathers (n=136) | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | all services | | consultations only | | all services | | consultations only | |
| | | | estimate | ratio, after/before (95% CI) | estimate | ratio, after/before (95% CI) | estimate | ratio, after/before (95% CI) | estimate | ratio, after/before (95% CI) |
| **a) services** | | | | | | | | | | |
| primary | *before* | | 5.92 | | 3.21 | | 0.71 | | 0.66 | |
| | after | - early | 11.65 | 1.97 (1.76 - 2.23) | 5.71 | 1.78 (1.57 - 2.02) | 0.54 | 1.73 (1.36 - 2.29) | 0.52 | 1.57 (1.28 - 1.91) |
| | | - delayed | 7.57 | 1.28 (1.15 - 1.42) | 3.97 | 1.24 (1.11 - 1.43) | 0.76 | 1.20 (0.99 - 1.45) | 0.68 | 1.26 (1.05 - 1.52) |
| | | - overall | 8.26 | 1.40 (1.27 - 1.54) | 4.26 | 1.33 (1.20 - 1.50) | 0.73 | 1.29 (1.07 - 1.55) | 0.66 | 1.31 (1.10 - 1.55) |
| mental | *before* | | 0.46 | | 0.43 | | 0.71 | | 0.66 | |
| | after | - early | 3.25 | 7.00 (3.86 - 19.02) | 2.98 | 6.88 (3.84 - 18.95) | 0.54 | 0.77 [a] | 0.52 | 0.78 [a] |
| | | - delayed | 1.48 | 3.20 (1.49 - 9.49) | 1.38 | 3.19 (1.45 - 9.60) | 0.76 | 1.07 [a] | 0.68 | 1.03 [a] |
| | | - overall | 1.78 | 3.84 (1.95 - 11.21) | 1.65 | 3.82 (1.94 - 11.18) | 0.73 | 1.03 [a] | 0.66 | 1.00 [a] |
| somatic | *before* | | 1.58 | | 1.52 | | 1.31 | | 1.26 | |
| | after | - early | 1.48 | 0.93 (0.74 - 1.20) | 1.43 | 0.94 (0.75 - 1.21) | 1.64 | 1.25 (0.77 - 2.18) | 1.59 | 1.26 (0.75 - 2.19) |
| | | - delayed | 1.77 | 1.12 (0.86 - 1.44) | 1.67 | 1.10 (0.84 - 1.44) | 1.36 | 1.04 (0.75 - 1.51) | 1.30 | 1.03 (0.73 - 1.48) |
| | | - overall | 1.72 | 1.09 (0.85 - 1.37) | 1.63 | 1.08 (0.84 - 1.37) | 1.41 | 1.07 (0.79 - 1.52) | 1.35 | 1.07 (0.78 - 1.52) |
| **b) individuals** | | | | | | | | | | |
| primary | *before* | | 0.74 | | 0.63 | | 0.56 | | 0.49 | |
| | after | - early | 0.88 | 1.19 (1.13 - 1.25) | 0.79 | 1.26 (1.17 - 1.34) | 0.74 | 1.31 (1.16 - 1.48) | 0.66 | 1.36 (1.18 - 1.57) |
| | | - delayed | 0.79 | 1.07 (1.03 - 1.11) | 0.69 | 1.10 (1.04 - 1.16) | 0.62 | 1.11 (1.02 - 1.21) | 0.53 | 1.10 (0.99 - 1.21) |
| | | - overall | 0.80 | 1.09 (1.05 - 1.13) | 0.70 | 1.12 (1.07 - 1.18) | 0.64 | 1.14 (1.05 - 1.24) | 0.55 | 1.14 (1.04 - 1.26) |
| mental | *before* | | 0.03 | | 0.03 | | 0.03 | | 0.03 | |
| | after | - early | 0.22 | 6.68 (3.86 - 12.00) | 0.22 | 6.55 (3.78 - 11.65) | 0.08 | 3.14 (1.33 - 6.86) | 0.08 | 3.14 (1.35 - 6.86) |
| | | - delayed | 0.12 | 3.49 (2.00 - 6.38) | 0.11 | 3.33 (1.90 - 6.12) | 0.05 | 1.89 (0.84 - 3.96) | 0.05 | 1.77 (0.73 - 3.60) |
| | | - overall | 0.13 | 4.02 (2.34 - 7.22) | 0.13 | 3.86 (2.25 - 6.92) | 0.05 | 2.10 (0.95 - 4.18) | 0.05 | 2.00 (0.86 - 3.75) |
| somatic | *before* | | 0.35 | | 0.34 | | 0.28 | | 0.27 | |
| | after | - early | 0.34 | 0.98 (0.82 - 1.15) | 0.34 | 0.99 (0.83 - 1.16) | 0.28 | 1.01 (0.80 - 1.24) | 0.27 | 1.00 (0.78 - 1.23) |
| | | - delayed | 0.34 | 0.99 (0.89 - 1.12) | 0.34 | 0.99 (0.88 - 1.11) | 0.30 | 1.08 (0.90 - 1.29) | 0.30 | 1.08 (0.89 - 1.29) |
| | | - overall | 0.34 | 0.99 (0.89 - 1.11) | 0.34 | 0.99 (0.88 - 1.10) | 0.30 | 1.07 (0.91 - 1.26) | 0.29 | 1.07 (0.90 - 1.26) |

primary: primary healthcare, mental: specialized mental healthcare, somatic: specialized somatic healthcare.

[a] Ratio could not be reliably bootstrapped in our model.

***Supplementary table 5*** – Reasons for accessing primary healthcare services, according to ICPC-2, before and after the terrorist attack. Categories with incidence of < 0.2 services per person per year are pooled. Supplement to Figure 4.

| | | mothers (n=222) | | | fathers (n=136) | | |
|---|---|---|---|---|---|---|---|
| | ICPC-2 | before | early | delayed | before | early | delayed |
| Overall | | 5.90 | 11.54 | 7.56 | 4.28 | 7.09 | 5.15 |
| General and unspecified | (A) | 0.91 | 0.94 | 1.06 | 0.50 | 0.88 | 0.67 |
| Digestive | (D) | 0.22 | 0.19 | 0.31 | 0.26 | 0.10 | 0.29 |
| Cardiovascular | (K) | 0.29 | 0.29 | 0.51 | 0.55 | 0.76 | 0.65 |
| Musculoskeletal | (L) | 1.36 | 1.21 | 1.60 | 1.10 | 0.84 | 1.07 |
| Psychological | (P) | 0.80 | 6.47 | 1.63 | 0.36 | 2.50 | 0.83 |
| Respiratory | (R) | 0.62 | 0.86 | 0.74 | 0.45 | 0.76 | 0.39 |
| Skin | (S) | 0.26 | 0.14 | 0.28 | 0.25 | 0.28 | 0.38 |
| Endocrine/Metabolic and Nutritional | (T) | 0.32 | 0.26 | 0.37 | 0.34 | 0.57 | 0.36 |
| Other | | 1.13 | 1.19 | 1.05 | 0.47 | 0.38 | 0.51 |

# PAPER 3

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CLINICAL RESEARCH ARTICLE

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# Does posttraumatic stress predict frequency of general practitioner visits in parents of terrorism survivors? A longitudinal study

Jon Magnus Haga[a,b], Lise Eilin Stene[a,c], Siri Thoresen[a], Tore Wentzel-Larsen[a,d] and Grete Dyb[a,b]

[a]Norwegian Centre of Violence and Traumatic Stress Studies (NKVTS), Oslo, Norway; [b]Institute of Clinical Medicine, Faculty of Medicine, University of Oslo, Oslo, Norway; [c]Department of Social Paediatrics, Division of Paediatric and Adolescent Medicine, Oslo University Hospital, Oslo, Norway; [d]Centre for Child and Adolescent Mental Health, Eastern and Southern Norway, Oslo, Norway

## ABSTRACT

**Background**: Life threat to children may induce severe posttraumatic stress reactions (PTSR) in parents. Troubled mothers and fathers may turn to their general practitioner (GP) for help.
**Objective**: This study investigated frequency of GP visits in mothers and fathers of adolescent and young adult terrorism survivors related to their own PTSR and PTSR in their surviving children.
**Method**: Self-reported early PTSR (4–5 months post-disaster) in 196 mothers, 113 fathers and 240 survivors of the 2011 Utøya terrorist attack were linked to parents' three years pre- and post-disaster primary healthcare data from a national reimbursement claims database. Frequency of parents' GP visits was regressed on parent and child PTSR, first separately, then in combination, and finally by including an interaction. Negative binominal regressions, adjusted for parents' pre-disaster GP visits and socio-demography, were performed separately for mothers and fathers and for the early (<6 months) and delayed (6–36 months) aftermath of the terrorist attack.
**Results**: Parents' early PTSR were significantly associated with higher early frequency of GP visits in mothers (rate ratio, RR = 1.31, 95%CI 1.09–1.56) and fathers (RR = 1.40, 95%CI 1.03–1.91). In the delayed aftermath, early PTSR were significantly associated with higher frequency of GP visits in mothers only (RR = 1.21, 95%CI 1.04–1.41). Early PTSR in children were not significantly associated with an overall increase in GP visits. On the contrary, in mothers, child PTSR predicted significant decrease in GP visits the delayed aftermath (RR = 0.83, 95% CI 0.71–0.97).
**Conclusions**: Our study suggests that GPs may play an important role in identifying and providing for parents' post-disaster healthcare needs. GPs need to be aware that distressed individuals are likely to approach them following disasters and must prepare for both short- and long-term healthcare needs.

## ¿El estrés postraumático predice la frecuencia de las visitas al médico de cabecera después de un desastre (GP) en las madres y los padres de los supervivientes de terrorismo? - un estudio longitudinal

**Planteamiento:** Las amenazas vitales a los niños puede inducir graves reacciones de estrés postraumático (PTSR, siglas en inglés de *posttraumatic stress reactions*) en los padres. Las madres y los padres preocupados pueden recurrir a su médico de cabecera (GP, siglas en inglés de *general practitioner*) en busca de ayuda.
**Objetivo:** Este estudio investigó la frecuencia de visitas al GP por parte de madres y padres de adolescentes y adultos jóvenes supervivientes del terrorismo relacionados con las reacciones de estrés postraumático propias y de sus hijos supervivientes.
**Métodos:** Los autoinformes de reacciones tempranas de estrés postraumático (4-5 meses después del desastre) en 196 madres, 113 padres y 240 supervivientes del ataque terrorista de Utøya de 2011 se enlazaron con los datos de atención primaria de salud de los padres (tres años antes y después del desastre) provenientes de una base de datos nacional de reclamaciones de reembolso. Se hizo una regresión de la frecuencia de las visitas al GP de los padres mediante regresiones binomiales negativas con las PTSR de los padres y el hijo, primero por separado, luego en combinación, y finalmente con la inclusión de una interacción. Los análisis se realizaron por separado para las madres y los padres con respecto a las consecuencias tempranas (<6 meses) y tardías (6-36 meses) después del ataque terrorista y se ajustaron para las visitas pre-desastre al GP de los padres y la sociodemografía.
**Resultados:** Las PTSR tempranas de los padres se asociaron significativamente con una mayor frecuencia temprana de visitas al GP en las madres (RR = 1,31, IC del 95%: 1,09-1,56) y padres (RR = 1,40, IC del 95%: 1,03-1,91). En las consecuencias posteriores, las PTSR tempranas se asociaron significativamente con una mayor frecuencia de visitas al GP en

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**PALABRAS CLAVE**
Desastre; Terrorismo; Padres; Médico de cabecera; Atención sanitaria; Trastorno por estrés postraumático (TEPT); Exposición indirecta; Trauma infantil; Traumatización; Necesidades sanitarias no cubiertas

**关键词**
灾难; 恐怖主义; 家长; 全科医生; 处理健康护理; 创伤后压力心理障碍; 间接暴露; 儿童创伤; 精神创伤; 未被满足的健康护理需求

**HGHLIGHTS**

- Posttraumatic stress reactions predicted increased frequency of early post-disaster GP visits in both mothers and fathers, suggesting that GPs play an important role in providing for post-disaster healthcare needs in parents and their families.
- Distressed mothers of traumatized survivors may be at increased risk of being underserved in the delayed aftermath of a disaster, calling for attention from GPs.

**CONTACT** Jon Magnus Haga, j.m.haga@medisin.uio.no Norwegian Centre of Violence and Traumatic Stress Studies (NKVTS), Oslo, Norway

**Geolocation information**: Utøya (60°01′25.0″N 10°14′50.0″E)

Supplemental data for this article can be accessed here.

madres solamente (RR = 1,21; IC del 95%: 1,04-1,41). Las PTSR tempranas en niños no se asociaron significativamente con un aumento general de las visitas al GP. De hecho, en las madres, las PTSR del hijo predijeron una disminución significativa en las consecuencias tardías (RR = 0,83; IC del 95%: 0,71-0,97).

**Conclusiones:** Nuestro estudio sugiere que los médicos de cabecera pueden desempeñar un papel importante a la hora de identificar y la proporcionar las necesidades de atención médica de los padres después de un desastre. Los médicos de cabecera deben ser conscientes de que las personas angustiadas es probable que se acerquen a ellos después de los desastres y deben prepararse para las necesidades de salud a corto y largo plazo.

### 标题：创伤后应激压力能够预测恐怖袭击幸存者的父母亲们在灾难后探访全科医生（GP）的频率吗？———个纵向研究

**背景**：孩子受到生命威胁后家长会产生严重的创伤后压力反应（PTSR）。困扰的家长可能会寻求全科医生(GP)的帮助。

**目标**：这个研究考察了处于青春期和成年早期的恐怖袭击幸存者的家长因为自身或者子女的PTSR而去探访全科医生的频率。

**方法**：2011年于特岛恐怖袭击中的196名母亲和113名父亲和240名幸存者的自我报告早期PTSR（灾难后4-6月），将这些自我报告与从国家索偿数据系统家长灾难3年之前和灾难之后的初级健康护理数据相联系。 先分别对家长探访全科医生的频率在家长与儿童的PTSR上进行负二项回归，再合并进行回归分析，最后检查了交互作用。恐怖袭击后的早期(<6个月)和后期（6-36月）的父亲母亲数据被分别进行检验分析，并控制了灾难前的家长探访GP次数和社会人口统计学变量。

**结果**：家长早期的PTSR显著地与母亲早期更高的GP探访率有关（rate ratio，RR=1.31，95%CI 1.09-1.56），也与父亲有关（RR=1.40，95%CI 1.03-1.91）。在灾难发生后期的比较中，早期PTSR只与母亲的高探访率有关（RR=1.21, 95%CI 1.04-1.41）。儿童的早期PTSR与GP探访率的整体增加无关。实际上，灾难发生后期儿童PTSR显著预测母亲探访率的下降（RR=0.83, 95%CI 0.71-0.97）。

**结论**：我们的研究表明全科医生在识别家长的创伤后健康关怀需求和提供帮助上有重要作用。全科医生需要知道在灾难后处于压力中的个体更可能探访，并且为应对短期和长期的健康关怀需要做好准备。

## 1. Background

Life threat to offspring may deeply affect their parents. Uncertainty of whether one's child will live or die, the sense of powerlessness to protect a loved one and the fear of what comes next may leave harsh, lasting impressions in mothers and fathers of children of all ages, including parents of teens and young adults. The relief of reunion following a traumatic event may be accompanied by a second wave of emotional turmoil in parents: the shock of reconnecting with an injured, distressed and poorly-functioning child. Numerous challenges lie ahead for the traumatized family. Great responsibilities fall on the shoulders of parents. First, parents need to learn how to cope with their own stress reactions. Second, parents need to learn how to support their child under difficult circumstances. Third, practical challenges may arise as family members resume their daily lives, return to school, work and social arenas (Røkholt, Schultz, & Langballe, 2016). Adequate healthcare services may be critical in this demanding situation.

Parent traumatization through life threat to their child has mainly been studied in contexts of child's chronic or acute illness (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009; Nelson & Gold, 2012) and sexual abuse (Dyb, Holen, Steinberg, Rodriguez, & Pynoos, 2003). High levels of parent posttraumatic stress reactions (PTSR) have consistently been reported. Few studies have addressed posttraumatic health in parents who learn that their offspring have been affected by disasters or terrorist attacks. One small study addressing 20 mothers of schoolchildren who survived the 2004 terrorist attack in Beslan reported high levels of PTSR, comparable to levels observed among the survivors themselves (Scrimin et al., 2006). A registry-based study of the aftermath of a pub fire in Holland in 2001 reported that mental and cardiovascular health problems, as recorded by the primary healthcare provider, were significantly more prevalent in parents of survivors with burns than in unaffected community controls (Dorn, Yzermans, Spreeuwenberg, & Van Der Zee, 2007). Thus, although limited, current evidence suggests that post-disaster ill-health in parents of disaster survivors may include both mental and somatic health problems that in turn may call for both mental and somatic post-disaster healthcare responses.

Our previous studies of the mothers and fathers of the 2011 Utøya terrorist attack survivors have demonstrated significantly elevated levels of early and lasting PTSR and depression/anxiety symptoms (Haga, Stene, Wentzel-Larsen, Thoresen, & Dyb, 2015; Thoresen, Jensen, Wentzel-Larsen, & Dyb, 2016). General practitioners (GPs) may play a key role in post-disaster management of parent mental and somatic healthcare needs, as a high number of individuals affected by a disaster may turn to their GP for help. Regardless of whether visits to the GP are related to the disaster or not, they allow GPs the opportunity to efficiently evaluate post-disaster healthcare needs.

Unmet healthcare needs are repeatedly reported following disasters (Brewin et al., 2010). A number of factors have been identified as barriers to post-disaster access to healthcare, including factors within the individuals in need (internal factors), as well as characteristics of the healthcare services or the community at large (external factors) (Kantor, Knefel, & Lueger-Schuster, 2016). Andersen's behavioural model of healthcare service utilization (Andersen, 1995) has shaped much of current thinking on access to healthcare. The model divides predictors of healthcare consumption into three groups: (1) predisposing factors, including sociodemographic characteristics of the individual; (2) illness-related needs factors, including symptom severity and perceived needs; and (3) enabling factors, including availability of services, patient attitude towards health seeking and financial resources. The family context of post-trauma healthcare acquisition has previously solely been addressed in terms of assessing sociodemographic factors of family members (Elhai, North, & Frueh, 2005; Gavrilovic, Schützwohl, Fazel, & Priebe, 2005; Rodriguez & Kohn, 2008), largely with inconclusive results. Family context of illness-related needs factors and post-trauma healthcare acquisition have, to our knowledge, never been addressed. As PTSR of a parent and child may share a common aetiology, and thus frequently coexist and mutually influence or interact with one another, the family context of PTSR may prove an important factor in determining parents' post-disaster GP-seeking behaviour.

In this study of the mothers and fathers of the 2011 Utøya terrorist attack survivors, we addressed frequency of parents' post-disaster GP visits related to parents' own PTSR and the PTSR experienced by their surviving adolescent or young adult child. Uniquely, the study combines registry-based longitudinal healthcare data before and after the attack, with self-reported distress in mothers, fathers and the survivors. Specifically, in regressions on parents' post-disaster GP visits, adjusted for pre-disaster GP visits and a selection of hypothesized predisposing and enabling sociodemographic factors, we addressed the following research question: Did early parent or child PTSR predict frequency of post-disaster GP visits in mothers or fathers in the early (< 6 months) or delayed (6–30 months) aftermath of the Utøya terrorist attack?

## 2. Methods

### 2.1. Setting

The setting of this study is the 3-year post-trauma aftermath of the Utøya terrorist attack. In the summer of 2011, the youth summer camp on Utøya Island was attacked by an armed terrorist. For more than an hour, young campers were trapped with the perpetrator on the island, with no means of self-defence, limited access to shelter and scarce chances of escaping from the island. The shooting spree left 69 dead. Nearly 500 survived, of whom 35 sustained severe physical injuries (Bugge et al., 2015). Their families, all physically distant from Utøya, followed the development of the attack through live news coverage and intermittent telecommunication with their children on the island. In the aftermath of the attack, survivors of Utøya were reunited with their families across all regions of Norway.

Post-disaster healthcare for parents was provided by the regular healthcare system in Norway (Ringard, Sagan, Sperre Saunes, & Lindahl, 2013). Primary healthcare is the first-line provider of healthcare in Norway, making primary diagnoses, treating diseases, issuing sickness certificates, prescribing drugs and referring patients to specialist care as required. Primary healthcare, including emergency primary healthcare, is accessible throughout the country, available 24/7, publicly funded and is the mandatory entry-point for the publicly funded specialized healthcare services in Norway. Following the Utøya terrorist attack, a proactive outreach programme was established in affected municipalities, as a supplement to the regular services (Dyb, Jensen, Glad, Nygaard, & Thoresen, 2014; Haga et al., 2015). Crisis teams in all affected municipalities were to provide the initial psychosocial support. Dedicated contact persons were to monitor healthcare needs throughout the first-year post-disaster and to facilitate access to care as needed. A majority of the parents had a dedicated contact person in the municipality (69.1%, $n$ = 206), of whom a majority was non-GP healthcare professionals (non-GP 89.1%, $n$ = 180; GP 7.5%, $n$ = 22; missing $n$ = 4). A minority of the parents had a contact person who was also their regular GP.

### 2.2. Design

This study is a part of the Utøya study, a three-wave longitudinal observational study of the survivors and the parents in the 3-year aftermath of the Utøya terrorist attack. The current paper combines registry-based data on parental GP visits in the three years before and after the terrorist attack (22 July 2008 to 21 July 2014) with self-reported data by mothers, fathers and survivors at 4–5 months post-disaster.

## 2.3. Procedure

Recruitment to the study was based on police records of the survivors ($n$ = 495). Survivors 13–33 years old ($n$ = 482) were asked to name their caregivers. All caregivers nominated, henceforth referred to as parents irrespective of their legal, social or biological status, were invited to participate, along with their associated survivors. All invitations were distributed by mail and included information on the study and how to opt out. The survivors and the parents of the survivors born in 1992 or later were invited to participate in face-to-face interviews. Parents of older survivors (born in 1991 or earlier) and parents not available for interview participated through questionnaires. Interviews were conducted by trained healthcare professionals in the home of the informant or at an alternative place at the convenience of the informant.

The overall study comprised three waves of data collection. Waves 1 and 2 were open cohorts; invitations were extended to all survivors and their caregivers. Wave 3 was a closed cohort; only participants in at least one of the two previous waves were invited. This paper reports on parents that participated in both Waves 1 and 3, and on their respective child survivors. Data collection for Wave 1 commenced in early November 2011 and was largely completed (>95%) by mid-December 2011, five months after the attack. Wave 3 commenced in late March 2014, and was largely completed (>95%) by mid-July 2014, three years after the attacks. Registry-based healthcare data was collected from consenting participants following Wave 3.

All consents were provided in writing. The Regional Committees for Medical and Health Research Ethics in Norway approved the study.

## 2.4. Participation

Overall, 299 mothers and 233 fathers ($n$ = 532 parents) participated in at least one of the three waves of the Utøya study, representing 68.7% ($n$ = 331) of the survivors (13–33 years, $n$ = 482). Two-thirds of the mother sample ($n$ = 196, 65.6%) and half of the father sample ($n$ = 113, 48.5%) met the inclusion criteria for this study (participated in Waves 1 and 3 and consented to sharing registry-based data), a majority of whom had participated through face-to-face interviews (mothers $n$ = 152, 77.6%; fathers $n$ = 88, 77.9%). Attrition in respect to the overall parent sample was significantly associated with male gender (OR 1.96, 95%CI 1.47–2.62, $p$ < .001), but not with level of education, perceived financial status, country of origin, whether living alone/with a partner or PTSR, in adjusted regressions (Supplemental data Table 1a-b). All parents included in this study cared for one or more survivors of the terrorist attack. In a majority of the parent participants (mothers $n$ = 190, 96.9%; fathers $n$ = 108, 95.6%), one or more of their surviving children participated alongside. In the remaining 11 parents, the surviving children did not participate. The child survivor sample ($n$ = 240) was gender balanced (female $n$ = 118, 49.2%; male $n$ = 122, 50.8%). No distinction was made between mothers and fathers parenting sons, daughters or both. Five parents additionally experienced the loss of a child to the terrorist attack (1.6%).

## 2.5. Measures

Primary healthcare consumption was assessed through the Health Economics Administration (HELFO) database of reimbursement claims to the national insurance scheme. The register contains all GP services provided in Norway as a part of the regular GP scheme. At the time of the Utøya attack, most people in Norway were part of the regular GP scheme (99.6%) (The Norwegian Directorate of Health, 2012). All GP contacts dating from 22 July 2008 to 21 July 2014 were excerpted, irrespective of whether services were provided at a GP clinic, through house calls, by regular GPs or locum GPs, within regular office hours or when on-call. Consultations with other professionals, including nurses, psychologists, therapists and counsellors, were not collected. A total of 13,419 GP contacts were identified, of which 42 (0.3%) were duplicates, i.e. referring to the same appointments (matching date, time, diagnosis, provider and mode of contact). Of the remaining 13,377 unique entries of primary healthcare services, 7212 (53.9%) were in-person consultations with a GP (GP visits). Non-in-person contacts, including telephone or mail correspondence between patient and GP, administrative renewal of sickness certificates, communication between the GP and other healthcare providers or the Norwegian Labor and Welfare Administration, were not included. Data on admittance and discharge of the participants from hospitals in Norway was collected from the Norwegian Patient Registry (NPR).

PTSR of the past month, recorded at Wave 1 in both parents and survivors, were evaluated by the 20-item University of California, Los Angeles Posttraumatic Stress Disorder Reaction Index (UCLA PTSD-RI) (Steinberg, Brymer, Decker, & Pynoos, 2004). The questions were formulated to explicitly relate to the terrorist attack. Responses were recorded on a five-point Likert-type scale, ranging from 0 (never) to 4 (most of the time). Three symptoms were presented to the participants in terms of two alternatively formulated questions. The question attracting the higher frequency score was used in further analyses, reducing the number of items to 17. First, continuous PTSR average scores of the 17 items were calculated (possible range 0–4). Second, individuals with a probable posttraumatic stress disorder (PTSD) were identified by using the DSM-IV diagnostic criteria (American Psychiatric Association, 1994). Criterion A (exposure) was satisfied in all participants of this study. Criteria B (intrusion), C (avoidance) and D (arousal) were derived by grouping items related to these categories. Scores of 3 (often) and 4 (most of the time) were taken to indicate clinical complaints. If all diagnostic criteria were satisfied (i.e. ≥1 item for criterion B, ≥3 items for criterion C and ≥2 items for criterion D), parents were classified with full PTSD. Falling short of a full diagnosis, parents who satisfied two criteria were classified with partial PTSD. Missing values ≤25% within each sub-score were resolved by calculating mean scores of the remaining items. For one individual who had >25% missing values, PTSR were not assessed. Cronbach's α of the total scale was 0.89–0.93 for the three subsamples investigated (mothers, fathers, survivors).

Socio-demography was collected at Waves 1 and 3 and included gender, age (at the time of the attacks), country of birth, level of education (none, primary, secondary, vocational or higher education/university degree) and whether living alone or with a partner (at the time of Wave 1). Financial status was assessed on a five-point Likert-type scale. The parents rated financial status relative to the general population, ranging from 1 ('much better') to 5 ('much worse'). The responses were dichotomized into 'average or better' and 'below average'. Discrepancies between the waves were resolved by using the first value reported.

### 2.6. *Statistics*

In this paper, posttraumatic stress is reported both on a continuous scale (mean PTSR score, 0–4) and as a likely diagnosis (no, partial, full PTSD). Parents' primary healthcare consumption is reported as observed frequency of GP visits and as estimated rate ratio (RR) of GP visits based on regressions described below. Missing values remained <5% throughout the paper and are noted.

*Regressions*. Frequency of parents' post-disaster GP visits was evaluated though negative binomial regressions (NB) (Elhai, Calhoun, & Ford, 2008). NB is a generalized linear regression model, in which the dependent variable is counted within a given time period (e.g. number of GP consultations within a year). A key feature of NB is that it may accommodate overdispersion in count data, i.e. variance greater than mean value, as was observed in our dataset. Separate analyses were performed in mothers and fathers and for the early (<6 months) and delayed (6–36 months) aftermath of the Utøya terrorist attack. PTSR measured at 3–5 months post-disaster (Wave 1) was assumed to reflect early levels of distress and hence assumed to validly serve as proxy for 'early PTSR'. In parents caring for more than one surviving child, the child with the more severe PTSR was included in the regressions. In all regressions, PTSR were included on a continuous scale (mean PTSR score).

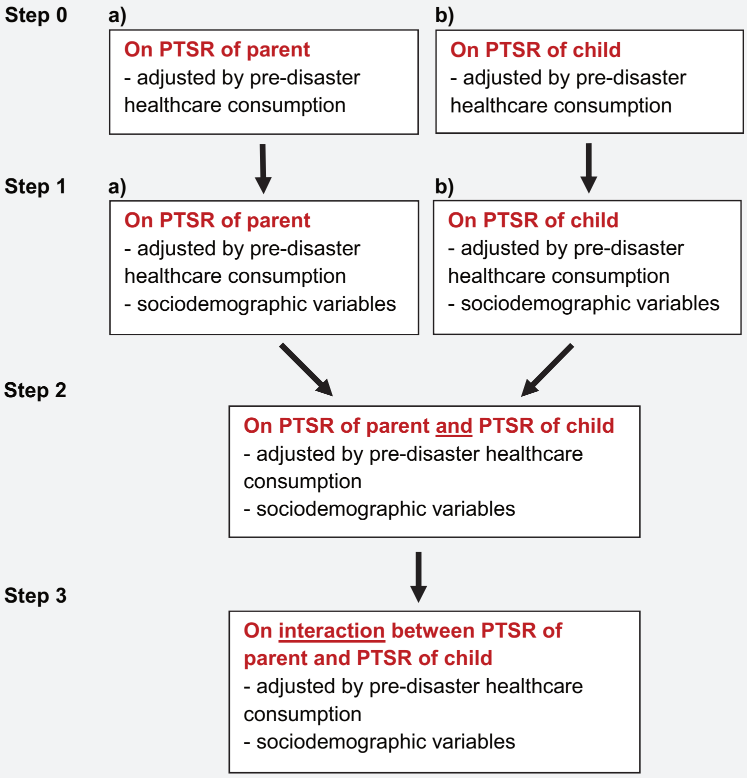

**Figure 1.** Overview of hierarchical regressions for parent primary healthcare consumption (frequency of GP visits).

Regressions were performed hierarchically (Figure 1). In all models, parents' GP visits were the outcome measure and their 3-year pre-disaster GP visits were adjusted for. First, we included as predictors the parents' early PTSR and, in a separate model, their child's early PTSR. Second, parents' sociodemographic status was included in the two models. Third, a model was assessed where both parent and child PTSR were included as well as the parents' sociodemographic status. Finally, the interaction between parent and child PTSR was added.

Regressions on count data needs to be offset for the logarithm of the persontime at risk, often referred to as the observational period. In our model, hospitalization was considered to make an individual unavailable for care from a GP. Thus, observational period was defined as days of non-admission to a healthcare institution. Null hypotheses were rejected at $p < .05$.

Analyses were performed with R-version-3.1.2 (R Foundation for Statistical Computing), with the R packages MASS (7.3–45) for negative binomial regressions and boot (1.3–13) for bootstrap analyses.

## 3. Results

The mothers ($n$ = 196) and fathers ($n$ = 113) participating in this study parented one ($n$ = 297, 96.1%), or more (n=12, 3.9%) survivors of the Utøya terrorist attack. Mean age (at time of attack) was 46.7 years (*SD* = 5.8) in mothers and 49.7 years (*SD* = 5.9) in fathers. Mean age (at time of attack) of their associated participating survivor ($n$ = 240) was 18.5 years (*SD* = 2.7). A majority of the parent participants cohabited with a partner ($n$ = 244, 79.7%, missing $n$ = 3) and rated their financial status as average or above ($n$ = 251, 81.2%). The parents were well educated (higher education, $n$ = 187, 60.5%) and largely of Norwegian origin ($n$ = 283, 91.6%).

PTSD classification of the parents and the PTSD classification of their surviving children are presented in Table 1. Notably, more than one in three mothers and one in eight fathers were classified with full or partial PTSD in the early post-disaster period. Furthermore, half of both mothers and fathers were found to care for a survivor classified as having either partial or full PTSD.

Figure 2 presents observed post-disaster frequencyof GP visits in parents according to their own PTSD classification. Both mothers and fathers had an observed higher post- than pre-disaster mean frequency of GP visits, irrespective of their PTSD classification, both in the early and delayed aftermath of the terrorist attack. This was, for most cases, confirmed by bootstrap $BC_a$ confidence intervals for ratios of means (Supplemental data Table 2). Notably, mean observed post-disaster frequency of GP visits increased according to parents' PTSD classification, hitting a maximum in individuals classified with full PTSD.

Figure 3 presents observed post-disaster frequency of GP visits in parents according to PTSD classification of their surviving child. In most cases, higher post- than pre-disaster frequency of GP visits was found. However, no apparent trend related to PTSD classification was observed.

Regressions of parent post-disaster frequency of GP visits related to parent and child early PTSR are presented in Figure 4. Notably, the separate models of PTSR in parent and child (Step 1) and the mutually adjusted models of PTSR in both parent and child (Step 2) returned similar conclusions and will be referred to collectively in the following. In the early aftermath of the attack, higher levels of early PTSR in parents predicted significantly higher frequency of GP visits in both mothers and fathers. In contrast, higher level of PTSR in their children did not. In the delayed aftermath, different patterns of primary healthcare consumption in mothers and fathers emerged. In mothers, higher levels of their own early PTSR predicted a significantly increased frequency of GP visits, while higher levels of their children's early PTSR predicted the reverse. In fathers, no significant association between frequency of GP visits in the delayed aftermath and early levels of PTSR was found. Instead, lower age, lower education and non-Norwegian origin were significantly associated with increased frequency of GP visits in fathers in the delayed aftermath. Taken together, mothers' levels of early distress

**Table 1.** Parent participants according to their own and their children's posttraumatic stress.

| Variables | mothers mean (*SD*)/*n* (%) | fathers mean (*SD*)/*n* (%) |
|---|---|---|
| **Parental distress** ($n$ = 196 mothers, $n$ = 112 fathers[a]) | | |
| PTSR score per item, mean (*SD*) | 1.35 (0.76) | 0.88 (0.63) |
| PTSD classification, *n* (%) | | |
| – full (3 criteria satisfied) | 18 (9.2) | 3 (2.7) |
| – partial (2 criteria satisfied) | 57 (29.1) | 12 (10.7) |
| – no (1 or 0 criteria satisfied) | 121 (61.7) | 97 (86.6) |
| **Distress in the child[b]** ($n$ = 190 mothers, $n$ = 108 fathers[c]) | | |
| Child PTSR score per item, mean (*SD*) | 1.55 (0.69) | 1.58 (0.67) |
| Child PTSD classification, *n* (%) | | |
| – full (3 criteria satisfied) | 16 (8.8) | 12 (10.9) |
| – partial (2 criteria satisfied) | 78 (41.5) | 45 (40.9) |
| – no (1 or 0 criteria satisfied) | 94 (50.0) | 51 (48.2) |

[a] Insufficient data on PTSR in $n$ = 1 father.
[b] Mean PTSR score of the survivor sample ($n$ = 219) was 1.54 (*SD* = 0.71), with full and partial PTSD classified in 21 (9.6%) and 85 (38.8%) survivors, respectively. The values are not directly comparable to the figures in Table 1, as not all survivors were represented by both a mother and a father. Furthermore, some of the survivors were siblings (parented by the same mother and father). In the case of siblings, the child with the higher PTSR score was included in the analyses.
[c] Missing data in $n$ = 6 mothers and $n$ = 4 fathers due to non-participation of their surviving child.

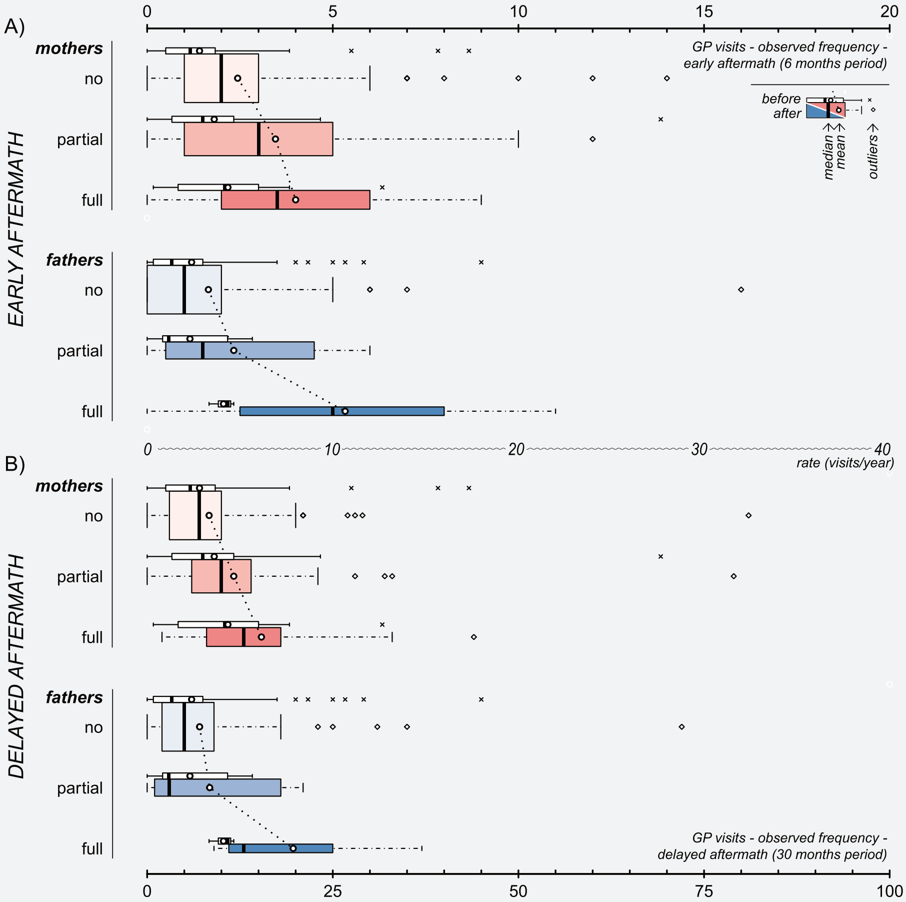

**Figure 2.** Observed post-disaster frequency of GP visits in mothers (red) and fathers (blue) in the early (A) and delayed (B) aftermath, according to parents' own PTSD classification. Panels A and B are drawn to scale in respect to annual rates, as indicated by the axis between the two panels. The width of the coloured boxes is proportional to the number of individuals within the subgroup. The corresponding pre-disaster values (white boxes) are included for reference purposes only.

significantly predicted their levels of GP visits both in the short and long term. Fathers' early levels of distress significantly predicted their levels of GP visits shortly after the attack, while being a younger father, being less educated and of non-Norwegian origin predicted the use of GP visits in the long term. Child distress significantly predicted lower levels of GP visits only in mothers in the delayed aftermath.

Children's distress was explored further in analyses of the interaction between child and parent PTSR as detailed in Figure 5. In neither model analysed, significant overall interactions were demonstrated ($p = .050$ for GP visits by fathers in the early aftermath, $p = .089$ for GP visits by mothers in the delayed aftermath and $p \geq .259$ in the remaining two models). However, the following trends were observed. In the early aftermath of the attack, early PTSR in children was significantly associated with higher frequency of GP visits in fathers with high, but not with low, levels of PTSR. In the delayed aftermath of the attack, early PTSR in children was significantly associated with lower frequency of GP visits in mothers with high, but not low, levels of PTSR.

A complete overview of output from all analyses (Step 0–4) is available in Supplemental data Table 3. Notably, in all regression models, pre-disaster frequency of GP visits was significantly associated with post-disaster frequency of GP visits ($p < .001$).

## 4. Discussion

This study of the parents of the 2011 Utøya terrorist attack survivors addressed associations between frequency of parents' post-disaster GP visits and the early PTSR endured by the parents and their surviving children. Our study demonstrated that traumatized mothers and fathers visited their GPs significantly more frequently than did their less affected peers in the first six months following the attack. Thus, our findings indicate an important potential role of GPs in identifying healthcare needs in distressed mothers and fathers early post disaster. The GPs need to be aware that traumatized parents approach them soon after a disaster, and that this is an important window of opportunity for reaching out to them. Parenting can be challenging in the wake of disaster. A wide range of health complaints and health related challenges, such as accessing social

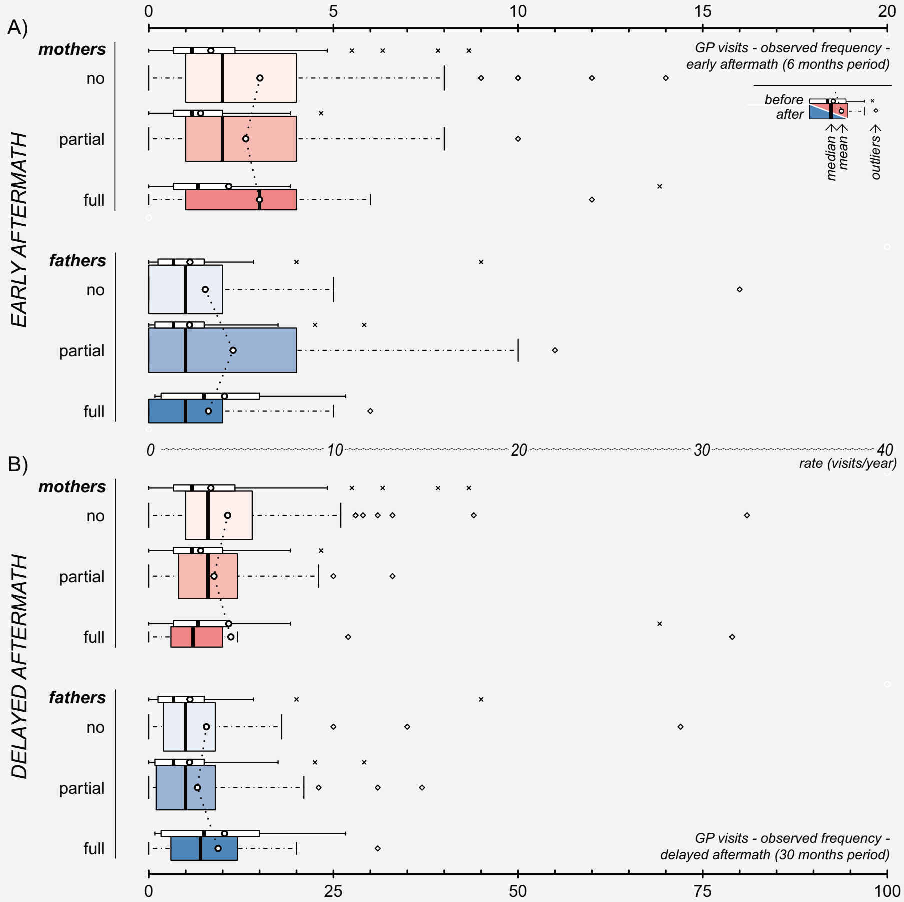

**Figure 3.** Observed post-disaster frequency of GP visits in mothers (red) and fathers (blue) in the early (A) and delayed (B) aftermath, according to the PTSD classification of their children. Panels A and B are drawn to scale in respect to annual rates, as indicated by the axis between the two panels. The width of the coloured boxes is proportional to the number of individuals within the subgroup. The corresponding pre-disaster values (white boxes) are included for reference purposes only.

benefits and welfare services, may trouble mothers and fathers as they struggle to regain normality. Post-disaster, distress may present both as somatic and mental health complaints (Dorn et al., 2007). Inexperienced providers may easily overlook the complexity of healthcare needs in individuals indirectly exposed to disaster, such as parents. In order for GPs to fulfil their important potential role in managing parents' healthcare needs in the early aftermath of disaster, the primary healthcare services need to prepare adequately for identifying post-disaster healthcare needs, providing appropriate evidence-based services and for making timely referrals.

Early PTSR potentially develop into chronic disease. PTSD may trouble individuals for years (Steinert, Hofmann, Leichsenring, & Kruse, 2015). Furthermore, traumatization may elicit a range of long-term somatic health complaints, including respiratory, gastrointestinal and cardiovascular disease (Boscarino, 2004; Pacella, Hruska, & Delahanty, 2013; Schnurr, Green, & Kaltman, 2007). Thus, GPs may continue to play an important role in monitoring and providing for traumatized parents, well beyond the early aftermath of a disaster. In line with this notion, own early distress was found to be significantly associated with lasting higher frequency of GP visits in mothers. In contrast, in fathers, no significant association was demonstrated in the delayed aftermath. Insufficient power of the latter analysis or the fact that distressed fathers may have had healthcare needs covered by other providers, such as specialized healthcare providers, may speak to this finding. An alternative interpretation is that distressed fathers, more than mothers, were reluctant to seek help for potential mental health issues, as has been found in several previous studies (Addis & Mahalik, 2003; Oliver, Pearson, Coe, & Gunnell, 2005). Post-disaster primary healthcare of fathers remains to be further investigated.

Healthcare needs in parents may reflect more than ill-health of the individual mother or father. Parents are the principal providers of care to their children, including adolescents and young adults (Grills-Taquechel, Littleton, & Axsom, 2011). Distress of traumatized children may directly influence healthcare needs in parents. Surprisingly, in our study, no significant overall increase in parents' frequency of

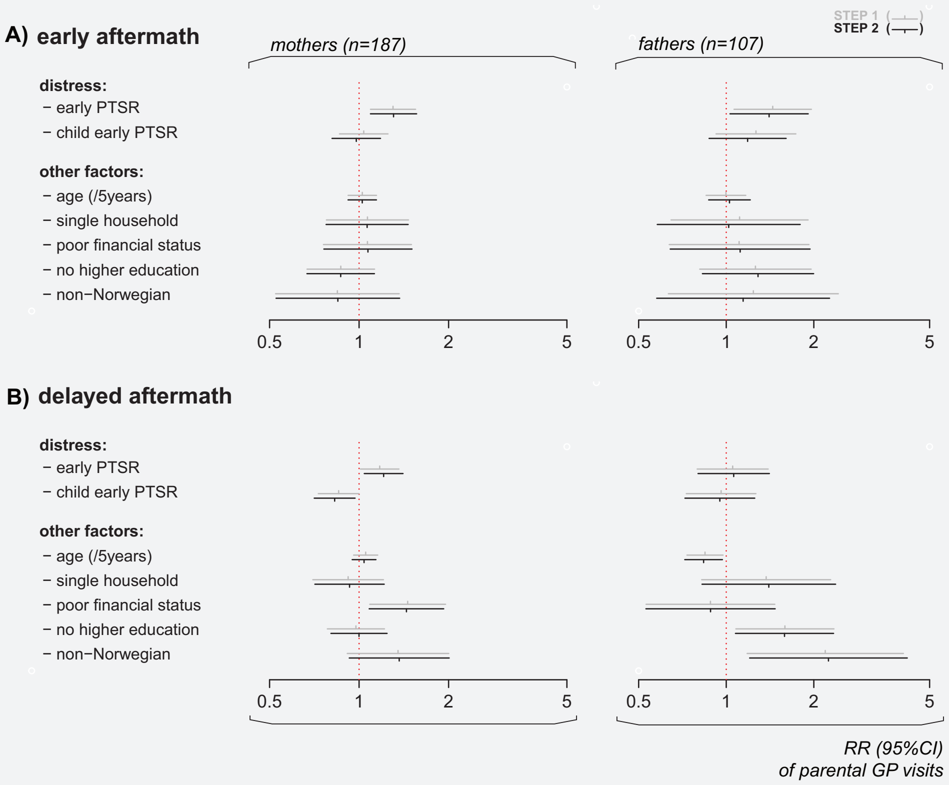

**Figure 4.** Frequency of GP visits in mothers and fathers in the early (A) and delayed (B) aftermath of the Utøya attack related to the parents' own and their children's early PTSR (estimated rate ratios (RR) with 95% confidence intervals). Hierarchical negative binomial regressions. Step 1: Regressions of parent and child PTSR in separate models, each adjusted for pre-disaster frequency of GP visits and socio-demography. Socio-demography shown in the chart stems from regressions of parent PTSR. Step 2: Regression of parent and child PTSR in a mutually adjusted model, including all variables from the previous step. All regressions were offset for observation time (non-admittance to hospital). Only individuals with no missing values were included. Horizontal dotted line: no relationship (RR = 1). Complete numerical figures available in Supplemental data Table 3.

GP visits related to survivors' early PTSR was found, neither in models adjusted nor unadjusted for parents' own early PTSR. On the contrary in mothers, higher levels of early PTSR in the survivors predicted significantly fewer GP visits among mothers in the delayed aftermath of the terrorist attack. One possible explanation is that mothers accompanying their children to healthcare services may have benefitted from such visits or been included in family treatment approaches. Thus, needs for primary healthcare services may potentially have been lower in mothers of the most distressed survivors. An alternative explanation is that mothers of troubled children may have focused on helping their child and potentially neglected their own healthcare needs.

We found no significant overall interactions. However, we observed some associations between child PTSR and frequency of parental GP visits. The associations differed between mothers and fathers and between the early and delayed aftermath, and should be interpreted with caution. Indications that the child's stress reactions may impact help seeking mainly in distressed parents, perhaps differently for mothers and fathers, need further exploration in future research before conclusions can be drawn.

Review of previous literature has suggested significantly higher post-trauma general healthcare consumption in adults experiencing higher levels of posttraumatic distress than in their peers experiencing lower levels of posttraumatic distress (Elhai et al., 2005), in line with our findings. However, previous literature may not directly compare to our study. Firstly, previous research on post-disaster healthcare consumption and PTSR in traumatized adults has been limited to adult survivors of trauma. To our knowledge, no studies have hitherto addressed post-disaster healthcare consumption related to self-reported distress symptoms in parents experiencing life threat to their child. Secondly, previous studies of adult survivors have largely analysed self-reported healthcare consumption, oftenwith dichotomous healthcare measures, rather than the observed frequencies of visits. Thirdly, few studies include information on pre-disaster healthcare consumption. In our study, all analyses were adjusted for pre-disaster frequency of GP visits, age, level of education, financial status, country of origin, whether living alone or with a partner and PTSR of the child survivor. Thus, our findings demonstrate not only a

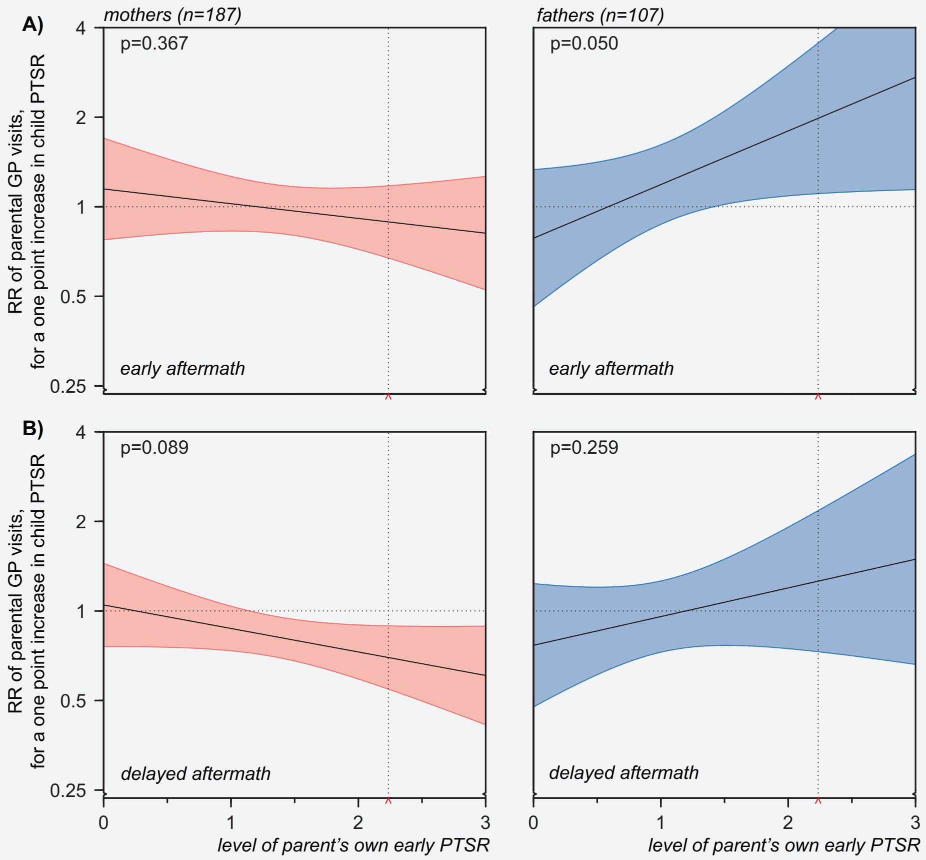

**Figure 5.** GP visits in mothers (red) and fathers (blue) related to interaction between parent and child early PTSR. The panels present the associations between frequency of parent's GP visits and their child's PTSR, across low through high levels of parent's own early PTSR, in the early (A) and delayed (B) aftermath of the Utøya terrorist attack. The horizontal dotted line indicates no relationship (rate ratio = 1). The 95% confidence intervals of rate ratios for parents' GP visits are visualized by colour shaded areas. For values of parent PTSR, where no overlap between the line of no relationship and the confidence intervals is observed, significant associations between child PTSR and the frequency of parental GP visits are indicated by the model. The vertical dotted line indicates the cut-off for probable PTSD diagnosis on the scale (mean PTSR score = 2.24, included for reference purposes only). P-values are overall estimates for interaction of each model.

significant association between parent distress and frequency of early post-disaster GP visits, but also that the associations appeared independently of adjustment for pre-disaster primary healthcare consumption, sociodemographic factors and the PTSR of their child survivor.

### 4.1. Strengths and limitations

This study combines registry-based healthcare data with self-reported distress in the mothers, fathers and their surviving children. We had the advantage of an objective outcome measure of healthcare consumption, as well as a detailed, subjective account of PTSR endured by the participants. Thus, uniquely, the study allowed for assessment of parents' healthcare consumption related to PTSR in a family context and the adjustment of analyses for participants' pre-disaster health-seeking behaviours. Pre- and post-disaster frequency of GP visits were assessed using administrative claims data that had been routinely reported by the GPs at the time of service provision. Thus, recall bias on behalf of the patient or the provider was eliminated. However, we cannot rule out aberrations in the GP records. For example, joint consultations of parents and children may erroneously have been registered as child or parent consultations only. Self-reports of PTSR were obtained from participants in Wave 1 of the study. As PTSR may have a fluctuating trajectory, cross-sectional assessment at the time of Wave 1 may not accurately represent the level of distress experienced throughout the early time period. Moreover, parent and child PTSR were measured on the same scale. However, as the scale was originally developed for investigations of adolescent samples, it has not been validated in adult populations.

In this study, the Utøya terrorist attack serves as a model for parent traumatization through indirect exposure to life threat to a child. The terrorist attack occurred within a limited time and space and the survivors were fairly homogenously exposed to the terrorist threat. Furthermore, none of the parents were in the proximity of the island at the time of attack nor were they threatened by the perpetrator. Thus, all parents were exposed to the terrorist threat exclusively through learning of the event. However, it should be noted that the 2011 Utøya terrorist attack happened in the aftermath of another terrorist attack, a bomb in the governmental quarter in Oslo, earlier the same day. Devastation, chaos and uncertainty following this blast may have added to the distress of some parents, in particular parents present in Oslo at the time.

Following the Utøya terrorist attack, primary healthcare was available across affected municipalities throughout the country, with few restrictions to the capacity of GPs to deliver care. We do not know to what extent the early proactive outreach programme influenced post-disaster doctor-seeking behaviours. The early proactive outreach programme may both have increased frequency of GP visits, by channelling more people to the services, as well as decreased the frequency of GP visits, by solving simple problems without the involvement of the regular healthcare services. In the minority of parents having their GP as a dedicated contact person, outreach services may have been reported as regular GP consultations to the HELFO database and hence included in our analyses. In Norway, referrals are obligatory for accessing specialized healthcare services. However, we may not rule out that some parents, due to the unprecedented nature of the terrorist attack, may have bypassed their GP and the regular referral system, e.g. with the help of their contact person in the municipality. Furthermore, irrespectively of mode of referral, individuals accessing specialized healthcare services may have had less of a need for primary healthcare services, as their primary healthcare needs may in part have been covered by their specialist provider. Finally, frequent GP visits are no guarantee for PTSR being recognized, let alone adequately provided for.

The ordered aftermath of the Utøya terrorist attack allowed for complete identification of all survivors at the time they were rescued from the island. The response rate among the survivors was high. Identifying the parent population was more challenging due to the diversity of modern family arrangements. However, unlike most studies of child and youth survivors, we were able to recruit both the mothers and fathers of a majority of the survivor participants. Nevertheless, despite the survivor population being known, the full size of the parent population remains unknown; survivors may have had additional caregivers to those identified by this study. Our analyses did not address cohabitation of parent and child. In survivors of this age group, a flexible and changeable cohabitation with parents may be expected. Youth may need to move temporarily or permanently to schools, universities or new workplaces. Nearly half of the parents of this cohort were divorced and sustained separate households (Haga et al., 2015). Thus, despite knowing that 60–70% of the survivors lived with one or more of their parents (Stene & Dyb, 2016), we had insufficiently accurate information on which of their parents they lived with and if they split their time between their different homes.

Our findings may be most applicable to comparable trauma and healthcare contexts. Whether our findings may be generalizable to healthcare needs that may arise in parents following life threat to offspring in the context of terrorism or natural disasters, accidents or serious illness of a child remains to be investigated.

All analyses were correlational. No causality can be demonstrated. We made no assessment of content or efficacy of the healthcare services provided.

### 4.2. Conclusion

Our study suggests that GPs may play a critical role both in identifying and in providing for the needs of traumatized parents of disaster survivors. GPs need to be aware that distressed individuals may be more likely to come to them in the aftermath of a disaster, and that this may be an important window in which to offer care. GPs must prepare for both short- and long-term healthcare needs. Distressed mothers of traumatized survivors may be at increased risk of being underserved in the delayed aftermath of a disaster, calling for the particular attention from GPs.

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## Disclosure statement

No potential conflict of interest was reported by the authors.

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## Notes on contributor

JMH, LES, ST and GD conceived of the study and developed the study design with TW-L. JMH, LES, ST and GD gathered the data. JMH and TW-L conducted the statistical analyses. JMH wrote the first draft of the paper. All authors contributed to further drafts and approved the final submission. JMH is the guarantor.

## Ethics approval and consent to participate

The study was approved by the Regional Committees for Medical and Health Research Ethics in Norway. Consent to participate was collected in writing from all participants.

## Availability of data and material

Data supporting the findings of this study are not publicly available. Self-reports may be accessed through the Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS). Administrative claims data on primary healthcare consumption and data from the Norwegian Patient Registry (NPR) may be accessed through the Norwegian Directorate of Health (https://helsedirektoratet.no/english). Restrictions apply. Technical appendix and statistical code are available from the corresponding author.

## ORCID

*Jon Magnus Haga* http://orcid.org/0000-0002-8805-1042

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**Supplementary Table 1:** Regressions of parent attrition, related to (a) sociodemograpy (analysed in the full parent cohort, n=532 parents), and to (b) early posttraumatic stress reactions (PTSR) (analysed in parent participants, whose participation included Wave 1, n=453 parents). Logistic regressions, odds ratio (OR) with 95% confidence intervals. Clustering of members of the same families was addressed by the gee-procedure with an exchangeable correlation structure in the regression analyses. Sociodemography for these analyses was derived from all three waves of data collection. Discrepancy between the waves was resolved by using the first value reported.

| **a)** | Unadjusted | | Adjusted[1] | |
|---|---|---|---|---|
| n=523 parents[2] | OR (95%CI) | p | OR (95%CI) | p |
| male gender | 1.96 (1.47-2.60) | < 0.001 | 1.96 (1.44-2.69) | < 0.001 |
| age (/5years) | 1.08 (0.93-1.25) | 0.302 | 0.98 (0.83-1.15) | 0.766 |
| single parent | 0.83 (0.51-1.34) | 0.441 | 1.06 (0.62-1.80) | 0.841 |
| no higher education | 0.99 (0.70-1.41) | 0.984 | 1.00 (0.70-1.41) | 0.981 |
| poor financial status | 0.54 (0.28-1.02) | 0.057 | 0.56 (0.29-1.10) | 0.091 |
| non-Norwegian origin | 0.69 (0.34-1.29) | 0.246 | 0.72 (0.37-1.39) | 0.766 |

[1] Adjusted regressions were adjusted for all variables shown.
[2] One or more missing variables were found in nine parents, who were consequently not included in the analyses (1.7%).

| **b)** | Unadjusted | | Adjusted[1] | |
|---|---|---|---|---|
| n=447 parents[2] | OR (95%CI) | p | OR (95%CI) | p |
| PTSR | 0.70 (0.51-0.95) | 0.023 | 0.88 (0.64-1.20) | 0.409 |

[1] Adjusted regressions were adjusted for gender, age, whether living alone or with a partner, higher education, financial status and country of origin (variables not shown).
[2] One or more missing variables were found in six parents, who were consequently not included in the analyses (1.3%).

**Supplementary Table 2:** Pairwise comparison of frequency of parents' GP visits before and after the terrorist attack according to parent's and child's posttraumatic stress disorder (PTSD) classification. RR= rate ratio, mean after by before disaster estimates. CI= bias-corrected and accelerated (BC$_a$) confidence intervals from bootstraps of 10,000 replications.

| | mothers (n=196) | | fathers (n=112) | |
|---|---|---|---|---|
| | rate, before/after | RR (95%CI) | rate, before/after | RR (95%CI) |
| EARLY AFTERMATH | | | | |
| *Parent distress* | | | | |
| - no PTSD | 2.82/4.88 | 1.73 (1.45-2.06) | 2.40/3.30 | 1.38 (1.10-1.68) |
| - partial PTSD | 3.61/6.91 | 1.91 (1.48-2.33) | 2.31/4.67 | 2.02 (0.87-3.58) |
| - full PTSD | 4.35/8.00 | 1.84 (1.20-2.85) | 4.11/10.67 | 2.59[a] |
| *Child distress* | | | | |
| - no PTSD | 3.31/5.94 | 1.79 (1.48-2.17) | 2.31/3.22 | 1.39 (1.04-1.79) |
| - partial PTSD | 2.85/5.38 | 1.89 (1.55-2.29) | 2.10/4.27 | 2.04 (1.48-2.78) |
| - full PTSD | 4.54/6.00 | 1.32 (0.92-2.13) | 4.42/3.33 | 0.75 (0.34-1.50) |
| DELAYED AFTERMATH | | | | |
| *Parent distress* | | | | |
| - no PTSD | 2.82/3.34 | 1.18 (1.00-1.55) | 2.40/2.82 | 1.18 (0.96-1.46) |
| - partial PTSD | 3.61/4.67 | 1.29 (1.10-1.54) | 2.31/3.37 | 1.46 (1.06-2.15) |
| - full PTSD | 4.35/6.16 | 1.41 (0.98-2.05) | 4.11/7.87 | 1.91[a] |
| *Child distress* | | | | |
| - no PTSD | 3.31/4.23 | 1.28 (1.06-1.67) | 2.31/3.18 | 1.38 (1.10-1.81) |
| - partial PTSD | 2.85/3.53 | 1.24 (1.06-1.46) | 2.10/2.44 | 1.16 (0.84-1.59) |
| - full PTSD | 4.54/4.65 | 1.02 (0.68-1.82) | 4.42/4.07 | 0.92 (0.53-1.61) |

[a] insufficient number of cases for reliable bootstrap

**Supplementary Table 3:** Frequency of GP visits in mothers and fathers in the early (A) and delayed (B) aftermath of the Utøya attack related to parents' own and their children's PTSR (estimated rate ratios, RR, with 95% confidence intervals). This table supplements Figure 4. Hierarchical negative binomial regressions: Step 0: Regressions of parent and child PTSR in separate models (A and B), each adjusted for pre-disaster GP visits. Step 1: Regressions of parent and child PTSR in separate models (A and B), each adjusted for parent's pre-disaster GP visits and sociodemography. Step 2: Regression of parent and child PTSR in one common, mutually adjusted model that included all variables of the previous step. Step 3: Regression of parent and child PTSR, and of the interaction between the two, in one common, mutually adjusted model that included all variables of the previous step. All analyses were offset for observation time (non-admittance to hospital).

|  | **Mothers (n=187)** |  | **Fathers (n=107)** |  |
|---|---|---|---|---|
| **STEP 0A** | RR (95% CI) | p | RR (95% CI) | p |
| *early aftermath* |  |  |  |  |
| - parent's early PTSR | 1.27 (1.08-1.50) | 0.004 | 1.49 (1.09-2.02) | 0.011 |
| - pre-disaster GP visits | 1.04 (1.03-1.06) | <0.001 | 1.06 (1.04-1.08) | <0.001 |
| *delayed aftermath* |  |  |  |  |
| - parent's early PTSR | 1.22 (1.06-1.42) | 0.007 | 1.11 (0.83-1.49) | 0.471 |
| - pre-disaster GP visits | 1.04 (1.03-1.05) | <0.001 | 1.06 (1.04-1.09) | <0.001 |
| **STEP 0B** | RR (95% CI) | p | RR (95% CI) | p |
| *early aftermath* |  |  |  |  |
| - child's early PTSR | 1.04 (0.87-1.26) | 0.661 | 1.24 (0.93-1.67) | 0.148 |
| - pre-disaster GP visits | 1.05 (1.04-1.06) | <0.001 | 1.06 (1.04-1.09) | <0.001 |
| *delayed aftermath* |  |  |  |  |
| - child's early PTSR | 0.86 (0.73-1.01) | 0.067 | 1.12 (0.86-1.47) | 0.397 |
| - pre-disaster GP visits | 1.04 (1.03-1.05) | <0.001 | 1.06 (1.04-1.08) | <0.001 |

| **STEP 1A** | RR (95% CI) | p | RR (95% CI) | p |
|---|---|---|---|---|
| *early aftermath* | | | | |
| - parent’s early PTSR | 1.30 (1.09-1.55) | 0.003 | 1.44 (1.06-1.96) | 0.019 |
| - age (/5years) | 1.03 (0.92-1.14) | 0.656 | 1.00 (0.85-1.17) | 0.976 |
| - single parent | 1.07 (0.78-1.47) | 0.689 | 1.11 (0.65-1.91) | 0.703 |
| - poor financial status | 1.07 (0.76-1.50) | 0.709 | 1.11 (0.64-1.92) | 0.718 |
| - no higher education | 0.87 (0.67-1.13) | 0.289 | 1.26 (0.81-1.96) | 0.304 |
| - non-Norwegian | 0.85 (0.52-1.36) | 0.492 | 1.24 (0.63-2.43) | 0.532 |
| - number of surviving children | 1.19 (0.72-1.97) | 0.502 | 0.68 (0.20-2.29) | 0.539 |
| - pre-disaster GP visits | 1.04 (1.03-1.06) | <0.001 | 1.05 (1.03-1.08) | <0.001 |
| | | | | |
| *delayed aftermath* | | | | |
| - parent’s early PTSR | 1.17 (1.01-1.36) | 0.036 | 1.05 (0.79-1.39) | 0.723 |
| - age (/5years) | 1.05 (0.96-1.16) | 0.283 | 0.85 (0.73-0.98) | 0.021 |
| - single parent | 0.92 (0.70-1.21) | 0.544 | 1.37 (0.82-2.29) | 0.225 |
| - poor financial status | 1.46 (1.09-1.95) | 0.012 | 0.88 (0.53-1.47) | 0.631 |
| - no higher education | 0.98 (0.78-1.22) | 0.829 | 1.59 (1.08-2.35) | 0.019 |
| - non-Norwegian | 1.35 (0.91-2.00) | 0.133 | 2.19 (1.18-4.06) | 0.013 |
| - number of surviving children | 0.88 (0.56-1.38) | 0.582 | 0.57 (0.20-1.66) | 0.304 |
| - pre-disaster GP visits | 1.03 (1.02-1.05) | <0.001 | 1.06 (1.04-1.08) | <0.001 |

| **STEP 1B** | RR (95% CI) | p | RR (95% CI) | p |
|---|---|---|---|---|
| *early aftermath* | | | | |
| - child’s early PTSR | 1.04 (0.86-1.25) | 0.706 | 1.27 (0.92-1.74) | 0.145 |
| - age (/5years) | 1.00 (0.90-1.13) | 0.908 | 1.05 (0.88-1.24) | 0.606 |
| - single parent | 1.06 (0.77-1.47) | 0.717 | 1.13 (0.64-2.01) | 0.262 |
| - poor financial status | 1.11 (0.78-1.57) | 0.568 | 1.08 (0.61-1.91) | 0.795 |
| - no higher education | 0.85 (0.77-1.12) | 0.717 | 1.30 (0.82-2.04) | 0.262 |
| - non-Norwegian | 0.99 (0.62-1.59) | 0.966 | 1.28 (0.64-2.58) | 0.490 |
| - number of surviving children | 1.11 (0.67-1.86) | 0.678 | 0.57 (0.16-1.99) | 0.379 |
| - pre-disaster GP visits | 1.05 (1.03-1.06) | <0.001 | 1.05 (1.03-1.08) | <0.001 |
| | | | | |
| *delayed aftermath* | | | | |
| - child’s early PTSR | 0.85 (0.73-1.00) | 0.049 | 0.96 (0.73-1.26) | 0.773 |
| - age (/5years) | 1.02 (0.93-1.12) | 0.676 | 0.84 (0.72-0.97) | 0.020 |
| - single parent | 0.93 (0.71-1.23) | 0.624 | 1.43 (0.84-2.42) | 0.186 |
| - poor financial status | 1.50 (1.12-2.01) | 0.006 | 0.89 (0.53-1.47) | 0.639 |
| - no higher education | 0.98 (0.79-1.22) | 0.868 | 1.58 (1.07-2.33) | 0.022 |
| - non-Norwegian | 1.56 (1.06-2.29) | 0.024 | 2.30 (1.24-4.29) | 0.008 |
| - number of surviving children | 0.84 (0.54-1.31) | 0.434 | 0.57 (0.20-1.65) | 0.299 |
| - pre-disaster GP visits | 1.04 (1.02-1.05) | <0.001 | 1.06 (1.04-1.08) | <0.001 |

| **STEP 2** | RR (95% CI) | p | RR (95% CI) | p |
|---|---|---|---|---|
| *early aftermath* | | | | |
| - parent’s early PTSR | 1.31 (1.09-1.56) | 0.003 | 1.40 (1.03-1.91) | 0.032 |
| - child’s early PTSR | 0.98 (0.81-1.18) | 0.822 | 1.18 (0.87-1.61) | 0.277 |
| - age (/5years) | 1.02 (0.92-1.14) | 0.662 | 1.03 (0.87-1.21) | 0.760 |
| - single parent | 1.06 (0.77-1.46) | 0.701 | 1.02 (0.58-1.80) | 0.946 |
| - poor financial status | 1.07 (0.76-1.51) | 0.693 | 1.12 (0.64-1.94) | 0.697 |
| - no higher education | 0.87 (0.67-1.13) | 0.286 | 1.29 (0.83-2.00) | 0.263 |
| - non-Norwegian | 0.85 (0.53-1.37) | 0.501 | 1.14 (0.58-2.27) | 0.702 |
| - number of surviving children | 1.19 (0.72-1.97) | 0.496 | 0.65 (0.19-2.18) | 0.486 |
| - pre-disaster GP visits | 1.04 (1.03-1.06) | <0.001 | 1.05 (1.03-1.08) | <0.001 |
| *delayed aftermath* | | | | |
| - parent’s early PTSR | 1.21 (1.04-1.41) | 0.013 | 1.06 (0.80-1.41) | 0.682 |
| - child’s early PTSR | 0.83 (0.71-0.97) | 0.019 | 0.95 (0.72-1.25) | 0.720 |
| - age (/5years) | 1.04 (0.95-1.14) | 0.413 | 0.84 (0.72-0.97) | 0.019 |
| - single parent | 0.93 (0.71-1.22) | 0.590 | 1.40 (0.83-2.38) | 0.212 |
| - poor financial status | 1.44 (1.08-1.93) | 0.013 | 0.88 (0.53-1.47) | 0.634 |
| - no higher education | 1.00 (0.80-1.24) | 0.996 | 1.59 (1.08-2.34) | 0.020 |
| - non-Norwegian | 1.36 (0.93-2.01) | 0.115 | 2.25 (1.20-4.19) | 0.011 |
| - number of surviving children | 0.90 (0.58-1.39) | 0.625 | 0.58 (0.20-1.69) | 0.320 |
| - pre-disaster GP visits | 1.03 (1.02-1.04) | <0.001 | 1.06 (1.04-1.08) | <0.001 |

| **STEP 3** | RR (95% CI) | p | RR (95% CI) | p |
|---|---|---|---|---|
| *early aftermath* | | | | |
| - parent’s early PTSR | 1.56 (1.01-2.41) | 0.045 | 0.71 (0.33-1.52) | 0.377 |
| - child early PTSR | 1.15 (0.77-1.70) | 0.493 | 0.78 (0.46-1.33) | 0.369 |
| - PTSR parent/child interaction | 0.89 (0.70-1.14) | 0.367 | 1.51 (1.00-2.29) | 0.050 |
| - age (/5years) | 1.03 (0.92-1.15) | 0.648 | 1.01 (0.86-1.19) | 0.872 |
| - single parent | 1.06 (0.77-1.46) | 0.709 | 0.89 (0.51-1.56) | 0.680 |
| - poor financial status | 1.10 (0.78-1.55) | 0.599 | 0.97 (0.56-1.68) | 0.915 |
| - no higher education | 0.87 (0.67-1.13) | 0.284 | 1.27 (0.82-1.96) | 0.282 |
| - non-Norwegian | 0.86 (0.54-1.39) | 0.542 | 1.04 (0.53-2.05) | 0.912 |
| - number of surviving children | 1.23 (0.74-2.03) | 0.424 | 0.71 (0.22-2.29) | 0.563 |
| - pre-disaster GP visits | 1.04 (1.03-1.06) | <0.001 | 1.05 (1.03-1.08) | <0.001 |
| *delayed aftermath* | | | | |
| - parent’s early PTSR | 1.62 (1.12-2.33) | 0.010 | 0.75 (0.38-1.47) | 0.409 |
| - child early PTSR | 1.05 (0.76-1.45) | 0.778 | 0.77 (0.48-1.24) | 0.275 |
| - PTSR parent/child interaction | 0.83 (0.68-1.03) | 0.089 | 1.25 (0.85-1.83) | 0.259 |
| - age (/5years) | 1.04 (0.95-1.14) | 0.422 | 0.84 (0.72-0.97) | 0.020 |
| - single parent | 0.92 (0.71-1.21) | 0.565 | 1.28 (0.75-2.18) | 0.364 |
| - poor financial status | 1.50 (1.12-2.00) | 0.006 | 0.83 (0.49-1.39) | 0.480 |
| - no higher education | 0.98 (0.79-1.22) | 0.872 | 1.56 (1.06-2.30) | 0.025 |
| - non-Norwegian | 1.38 (0.94-2.03) | 0.099 | 2.05 (1.10-3.82) | 0.024 |
| - number of surviving children | 0.93 (0.60-1.45) | 0.746 | 0.61 (0.21-1.74) | 0.354 |
| - pre-disaster GP visits | 1.03 (1.02-1.05) | <0.001 | 1.06 (1.04-1.08) | <0.001 |

# INTERVIEW GUIDE

## (in Norwegian only)

**This section is an excerpt of the full interview guide for the Utøya study and includes applicable items only. For detailed information on copyright licences and official translations, please contact principal investigator of the Utøya study, Professor Grete Dyb, MD/PhD.**

| | |
|---|---|
| **Prosjekt** | **1049372** |
| **Skjemanummer** | |

**ID** **NB! Skriv inn skjemanummer (id.nr.) og les det høyt opp på begynnelsen av intervjuet.**

Id-nr. .................................. ☐ 1

**RELASJON** **Relasjon til overlevende**

Mor/stemor ................................ ☐ 1
Far/stefar .................................. ☐ 2

# Kronologisk historie

**Jeg vet at sønnen/datteren din var på Utøya under terroranrepet. Fortell meg om dine opplevelser fra du hørte om skytingen på Utøya til du så ham/henne igjen.**

***Dersom informanten ikke svarer på det kan man si:***

**Fortell meg om øyeblikket før terroraksjonen startet.**

***La informanten fortelle mest mulig fritt.***

***Hjelp informanten videre ved å si:***

**Hva skjedde da?**

***Hjelp informanten til å utdype ved å si:***

**Fortell meg om det. Eller gjenta det siste de sa.**

**Q1** **Hva opplevde du?**

(Instruksjon, les opp):

**Nå har du fortalt meg om dine opplevelser i forbindelse med terrorangrepet på Utøya. Nå skal jeg stille deg noen mer detaljerte spørsmål om hva du opplevde. På disse spørsmålene trenger du bare å svare Ja eller Nei.**

| | Ja<br>1 | Nei<br>2 | |
|---|---|---|---|
| • Fikk du vite om bombingen i Oslo før skytingen på Utøya? ................................. | ☐ | ☐ | 1 |
| • Var du bekymret for noen i familien eller venn pga bombingen i Oslo? ....................... | ☐ | ☐ | 2 |
| • Hadde du telefonkontakt/smskontakt med sønnen/datteren din før han/hun kom i trygghet? .. | ☐ | ☐ | 3 |
| • Var du på mottaket på Sundvollen? ......................................................... | ☐ | ☐ | 4 |
| • Så du ungdommer som var alvorlig skadet? ............................................... | ☐ | ☐ | 5 |

## Reaksjoner under hendelsen

**Q3**

(Hjelp til intervjuer: Skytingen startet kl 17.22. Beredskapstroppen pågrep gjerningsmannen kl 18.27.)

**Når omtrent fikk du vite at sønnen/datteren din var i trygghet? Ca kl.**

Noter klokkeslett .................. ☐ / ☐ 1

**Q4** **Når ble du gjenforent med sønnen/datteren din?**

Fredag ca kl. ...................... ☐ / ☐ 1

Lørdag ca kl. ...................... ☐ / ☐ 2

**Q5** **Senere gjenforent**

Noter når ________________________________

________________________________

**Q6** **Ble nær venn eller familiemedlem drept på Utøya eller i regjeringskvartalet?**

Ja ........................................ ☐ 1

Nei ....................................... ☐ 2

HVIS JA

**Q7** **Hvem?**

Velg en kategori for hver av de drepte nære

| | Ja<br>1 | Nei<br>2 | |
|---|---|---|---|
| • Barn ........................... | ☐ | ☐ | 1 |
| • Søsken .......................... | ☐ | ☐ | 2 |
| • Annen familie .................. | ☐ | ☐ | 3 |
| • Ektefelle/partner/kjæreste ....... | ☐ | ☐ | 4 |
| • Nær venn ...................... | ☐ | ☐ | 5 |

**Q8** **Ble sønnen/datteren din fysisk skadet på Utøya?**

Ja ........................................ ☐ 1

Nei ....................................... ☐ 2

**Q9** **Ble en nær venn eller andre familiemedlemmer skadet på Utøya eller i regjeringskvartalet (slik at de ble behandlet i sykehus)?**

Ja ........................................ ☐ 1

Nei ....................................... ☐ 2

HVIS JA

**Q10** **Hvem?**

| | Ja<br>1 | Nei<br>2 | |
|---|---|---|---|
| • Barn ........................... | ☐ | ☐ | 1 |
| • Søsken .......................... | ☐ | ☐ | 2 |
| • Annen familie .................. | ☐ | ☐ | 3 |
| • Ektefeller/partner/kjæreste ...... | ☐ | ☐ | 4 |
| • Nær venn ...................... | ☐ | ☐ | 5 |

# Posttraumatiske stressreaksjoner

***(Instruksjon som leses opp:)***
**Nå har vi snakket om hendelsene og hva du opplevde da sønnen/datteren din var i fare på Utøya og like etterpå. Man kan få ulike reaksjoner på dramatiske hendelser. Nå kommer jeg til å lese opp noen påstander om mulige reaksjoner for foreldre etter terrorangrepet på Utøya 22. juli. For hver påstand vil jeg spørre deg hvor ofte du har opplevd å ha det slik DEN SISTE MÅNEDEN**

**Her er et skjema som er til hjelp når du skal svare på hvor ofte du har opplevd problemet den siste måneden.**

***(Ta frem frekvensarket og legg på bordet mellom dere. Gå gjennom de ulike alternativene før dere starter på listen).***

**Q11** **Hvor mye av tiden den siste måneden**

| | Aldri 1 | Sjelden 2 | Noen ganger 3 | Ofte 4 | Nesten alltid 5 | |
|---|---|---|---|---|---|---|
| • D4 Jeg er på vakt for fare eller ting jeg er redd for. | ☐ | ☐ | ☐ | ☐ | ☐ | 1 |
| • B4 Når noe minner meg om terrorangrepet, blir jeg veldig ute av meg, redd eller trist. | ☐ | ☐ | ☐ | ☐ | ☐ | 2 |
| • B1 Jeg får skremmende tanker, ser for meg bilder eller hører lyder fra terrorangrepet, selv om jeg ikke vil det. | ☐ | ☐ | ☐ | ☐ | ☐ | 3 |
| • D2 Jeg føler meg sur, sint eller rasende. | ☐ | ☐ | ☐ | ☐ | ☐ | 4 |
| • B2 Jeg drømmer om terrorangrepet eller har mareritt om andre ting | ☐ | ☐ | ☐ | ☐ | ☐ | 5 |
| • B3 Jeg føler at jeg er tilbake til da terrorangrepet skjedde, og opplever det om igjen. | ☐ | ☐ | ☐ | ☐ | ☐ | 6 |
| • C4 Jeg har lyst til å være alene og ikke sammen med venner. | ☐ | ☐ | ☐ | ☐ | ☐ | 7 |
| • C5 Jeg føler meg alene inni meg og føler ikke nærhet til andre mennesker. | ☐ | ☐ | ☐ | ☐ | ☐ | 8 |
| • C1 Jeg forsøker å ikke snakke om terrorangrepet, tenke på det eller ha følelser rundt det. | ☐ | ☐ | ☐ | ☐ | ☐ | 9 |
| • C6 Jeg har problemer med å føle glede eller kjærlighet. | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| • C6 Jeg har problemer med å føle tristhet eller sinne. | ☐ | ☐ | ☐ | ☐ | ☐ | 11 |
| • D5 Jeg blir lett urolig eller skvetter lett, for eksempel når jeg hører høye lyder eller når noe overrasker meg. | ☐ | ☐ | ☐ | ☐ | ☐ | 12 |
| • D1 Jeg har problemer med å få sove eller jeg våkner ofte om natten. | ☐ | ☐ | ☐ | ☐ | ☐ | 13 |
| • AF Jeg bebreider meg selv for noe av det som skjedde under terrorangrepet. | ☐ | ☐ | ☐ | ☐ | ☐ | 14 |
| • C3 Jeg har problemer med å huske viktige ting fra terrorangrepet. | ☐ | ☐ | ☐ | ☐ | ☐ | 15 |
| • D3 Jeg har problemer med å konsentrere meg eller være oppmerksom. | ☐ | ☐ | ☐ | ☐ | ☐ | 16 |
| • C2 Jeg forsøker å holde meg unna folk, steder eller ting som minner meg om terrorangrepet. | ☐ | ☐ | ☐ | ☐ | ☐ | 17 |
| • B5 Når noe minner meg om terrorangrepet, får jeg sterke følelser i kroppen, for eksempel at hjertet slår fort, eller at jeg får hodepine eller mageknip. | ☐ | ☐ | ☐ | ☐ | ☐ | 18 |
| • C7 Jeg tror ikke at jeg kommer til å leve lenge. | ☐ | ☐ | ☐ | ☐ | ☐ | 19 |
| • D2 Jeg krangler eller slåss mye | ☐ | ☐ | ☐ | ☐ | ☐ | 20 |

➠

| | Aldri | Sjelden | Noen ganger | Ofte | Nesten alltid | |
|---|---|---|---|---|---|---|
| • C7 Jeg er negativ eller pessimistisk når jeg tenker på fremtiden | ☐ | ☐ | ☐ | ☐ | ☐ | 21 |
| • AF Jeg er redd for at noe lignende som terrorangrepet skal skje igjen. | ☐ | ☐ | ☐ | ☐ | ☐ | 22 |
| • Nye D3 Jeg er sint på noen andre for at de ikke gjorde mer for å forhindre det som skjedde under terrorangrepet, eller for at de ikke har gjort nok etterpå (gjelder ikke sinne mot gjerningsmannen). | ☐ | ☐ | ☐ | ☐ | ☐ | 23 |
| • Nye D2 Jeg tenker at andre vonde ting vil skje med meg i fremtiden | ☐ | ☐ | ☐ | ☐ | ☐ | 24 |
| • Nye E2 Jeg gjør ting som skader eller kan skade meg selv eller andre. (For eksempel å kjøre for fort, bruke nakrotika, drikke veldig mye, skade meg selv eller gjøre andre farlige ting). | ☐ | ☐ | ☐ | ☐ | ☐ | 25 |
| • Nye D3 Jeg bebreider meg selv for at jeg ikke blir bedre igjen fortere. | ☐ | ☐ | ☐ | ☐ | ☐ | 26 |
| • Nye D4 Jeg skammer meg over noe av det som det som skjedde under terrorangrepet. | ☐ | ☐ | ☐ | ☐ | ☐ | 27 |
| • Nye D4 Det som hendte var så motbydelig og frastøtende at jeg føler meg dårlig, blir kvalm eller føler avsky når jeg tenker på det. | ☐ | ☐ | ☐ | ☐ | ☐ | 28 |
| • Nye D2 Jeg tenker at verden er utrygg, og at jeg ikke er godt nok beskyttet. | ☐ | ☐ | ☐ | ☐ | ☐ | 29 |
| • Nye D3 Jeg har sterke følelser om hevn | ☐ | ☐ | ☐ | ☐ | ☐ | 30 |
| • Nye D3 Jeg klandrer meg selv for at jeg lot det som skjedde på Utøya endre meg så mye. | ☐ | ☐ | ☐ | ☐ | ☐ | 31 |
| • Nye D4 Jeg føler meg veldig redd | ☐ | ☐ | ☐ | ☐ | ☐ | 32 |
| • Nye D2 Jeg tenker negativt om meg selv, for eksempel at jeg er et dårlig menneske, eller et menneske som ikke stoler på andre | ☐ | ☐ | ☐ | ☐ | ☐ | 33 |

## Depresjon og angst

**Q12**

Instruksjon: Les opp

**Jeg vil nå spørre deg om noen plager man kan ha, uten at de nødvendigvis er relatert til det man har opplevd. Angi i hvilken grad du har vært plaget av hvert enkelt problem i løpet av DE SISTE 14 DAGENE. Sett ett kryss for hver linje.**

| | Ikke plaget<br>1 | Litt plaget<br>2 | Ganske mye plaget<br>3 | Veldig mye plaget<br>4 | |
|---|---|---|---|---|---|
| • Stadig redd eller engstelig | ☐ | ☐ | ☐ | ☐ | 1 |
| • Nervøsitet, indre uro | ☐ | ☐ | ☐ | ☐ | 2 |
| • Følelse av håpløshet med tanke på fremtiden | ☐ | ☐ | ☐ | ☐ | 3 |
| • Nedtrykt, tungsindig | ☐ | ☐ | ☐ | ☐ | 4 |
| • Mye bekymret eller urolig | ☐ | ☐ | ☐ | ☐ | 5 |
| • Følelse av at alt er et slit | ☐ | ☐ | ☐ | ☐ | 6 |
| • Følelse av å være anspent, oppjaget | ☐ | ☐ | ☐ | ☐ | 7 |
| • Plutselig frykt uten grunn | ☐ | ☐ | ☐ | ☐ | 8 |
| • Tanker om å ta ditt liv | ☐ | ☐ | ☐ | ☐ | 9 |

**Her følger en del spørsmål foreldrene kan fylle ut selv. Husk å gjøre vurdering om udekket hjelpebehov og om neste kontakt før du avslutter!**

# Kontakt med hjelpeinstanser etter hendelsen

**Q21** **Tok noen fra kriseteamet eller andre ansatte fra kommunen/bydelen kontakt med deg rett etter hendelsen?**

Ja ........................................ ☐ 1
Nei ........................................ ☐ 2

**Q22** **Har du hatt en kontaktperson i kommunen/bydelen?**

Ja ........................................ ☐ 1
Nei ........................................ ☐ 2

**Q23**

| **Q23.A** Etter hendelsene på Utøya 22. juli, har du fått hjelp fra ...? | | | **Q23.B** Hvis ja, ca hvor mange ganger? | **Q23.C** I hvilken grad har denne hjelpen vært til nytte for deg? | | | |
|---|---|---|---|---|---|---|---|
| | **Ja** | **Nei** | **Noter antall** | Ikke i det hele tatt | I noen grad | I stor grad | |
| | 1 | 2 | | 1 | 2 | 3 | |
| • **Fastlegen din** ........................ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 1 |
| • **Andre hjelpepersoner i kommunen, for eksempel helsesøster, PPT, kommunepsykolog eller andre** ...... | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 2 |
| • **Psykolog eller psykiater i spesialisthelsetjenesten, for eksempel BUP, DPS eller andre** ..... | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 3 |
| • **Sjelesørger (prest, imam og lignende)** ............................ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 4 |

# Demografi:

**Nedenfor følger noen spørsmål om bosted, familieforhold, inntekt og lignende.**

**Q33** **Kjønn**

Kvinne ...................................... ☐ 1
Mann ...................................... ☐ 2

**Q34** **Antall fylte år pr. 22. juli 2011**

Noter alder ☐ 1

**Q35** **Antall egne barn**

Noter antall ☐ 1

**Q36** **Antall stebarn**

Noter antall ☐ 1

**Q37** **Hvor mange egne barn og stebarn hadde du på Utøya under terrorangrepet?**

Noter antall ☐ 1

**Q38** **Din relasjon til den/de overlevende:**

Forelder .................................... ☐ 1
Steforelder ................................ ☐ 2

**Q39** **Omsorgsgivere/foreldre i husholdet**

To foreldre til den overlevende ............... ☐ 01
En forelder og en steforelder ................. ☐ 02
En forelder .................................. ☐ 03

Annet, noter: ________________________________

________________________________

**Q40** **Hva er din høyeste fullførte utdanning/skolegang?**

Universitet/høyskole mer enn 4 år ☐ 1
Universitet /høyskole inntil 4 år ☐ 2
Studieforberedende opplæring, gymnas eller allmennfaglig studieretning på videregående skole ☐ 3
Yrkesfaglig opplæring, yrkesskole eller yrkesfaglig studieretning på videregående skole ☐ 4
Grunnskole ☐ 5
Ingen fullført utdannelse ☐ 6

**Q41** **Er du i arbeid (hel- eller deltid, minst 50%)?**

Ja ☐ 1
Nei ☐ 2

**Q42** **Er du student eller skoleelev (hel- eller deltid, minst 50%)?**

Ja ☐ 1
Nei ☐ 2

HVIS JA PÅ SPM. **q41** ELLER **q42**

**Q43** **Har du vært borte fra jobb/studier på grunn av fysiske eller psykiske plager i løpet av de siste 3 månedene?**

Ja ☐ 1
Nei ☐ 2

HVIS JA PÅ SPM. **q43**

**Q44** **Omtrent hvor mange dager med sykefravær har du hatt til sammen i denne perioden ?**

5 dager eller mindre ☐ 1
6-10 dager ☐ 2
11-20 dager ☐ 3
Mer enn 20 dager ☐ 4

**Q45** **Omtrent hva var din personlige brutto samlede inntekt i 2010? Altså all samlet inntekt før skatt og fradrag.**

Mindre enn kr. 300.000 ☐ 1
Mellom kr. 300. og 500.000 ☐ 2
Mer enn kr 500.000 ☐ 3
Vet ikke ☐ 4

**Q46** **Hvor god råd synes du at du har i forhold til folk flest?**

Mye bedre råd ☐ 1
Noe bedre råd ☐ 2
Omtrent som folk flest ☐ 3
Noe dårligere råd ☐ 4
Mye dårligere råd ☐ 5

**Q47** **Bor du alene eller sammen med noen?**

Alene ☐ 1
Sammen med noen ☐ 2

**Q48** **Hvis sammen med noen, hvem?**

| | Ja<br>1 | Nei<br>2 | |
|---|---|---|---|
| Ektefelle/samboer | ☐ | ☐ | 1 |
| Ett eller flere barn (under 18 år) | ☐ | ☐ | 2 |
| Andre familiemedlemmer | ☐ | ☐ | 3 |
| Andre voksne | ☐ | ☐ | 4 |

**Q49** **I hvilket land er du født? Norge?**

Ja ☐ 1
Nei ☐ 2

HVIS FØDT I ANNET LAND

**Q50** **Hvilket land ble du født i?**

Noter ________________________

________________________

**Q51** **I hvilket land er moren din født: Norge?**

Ja ☐ 1
Nei ☐ 2

HVIS MOREN DIN BLE FØDT I ANNET LAND

**Q52** **Hvilket land ble hun født i?**

Noter ________________________

________________________

**Q53** **I hvilket land er faren din født : Norge?**

Ja ☐ 1
Nei ☐ 2

HVIS FAREN DIN BLE FØDT I ANNET LAND

**Q54** **Hvilket land ble han født i?**

Noter ________________________

________________________

**Når du har fylt inn spørsmålene ovenfor, vil intervjuer avslutte med å diskutere hjelpebehov med deg.**

# Udekket hjelpebehov

## Spørsmålene nedenfor fylles ut av intervjuer i samråd med deg

**Q59**

Hvis informanten svarte litt eller mer plaget på spørsmål om «Tanker om å ta ditt liv» på **svar fra Q12.A.9** foretas en suicidalitetsvurdering hvor blant annet følgende momenter bør dekkes:

| | Ja<br>1 | Nei<br>2 | |
|---|---|---|---|
| Har du noen gang skadet deg selv? . | ☐ | ☐ | 1 |
| Hvis ja, har du skadet deg selv i løpet av de siste 14 dagene? . . . . . . . . . . . . . | ☐ | ☐ | 2 |
| Har du konkrete tanker om å ta ditt eget liv? . . . . . . . . . . . . . . . . . . . . . . . . . . . | ☐ | ☐ | 3 |
| Har du planer om å ta ditt eget liv? . . | ☐ | ☐ | 4 |

**FORETA EN KLINISK VURDERING AV EVENTUELT AKUTT HJELPEBEHOV.**

FOR ALLE

**Q60** **Får du dekket de behovene du mener du har for hjelp etter terrorangrepet (for eksempel fra psykolog, lege, sykepleier, sosial arbeider, eller andre profesjonelle)?**

Ja . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ☐ 1
Nei . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ☐ 2

**Q61** **Til intervjuer: Er det kommet fram noe i intervjuet som tilsier at du bør drøfte hjelpebehov med informanten?**

Ja . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ☐ 1
Nei . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ☐ 2

**Q62** **Hvis ja, hva ble konklusjonen på drøftelsen? (beskriv)**

Noter

**Q63** **Hvordan er dette fulgt opp av intervjueren?**

Dette kan for eksempel være at kontaktperson i kommunen er kontaktet og henviser informanten til psykisk helsevern, eller at man har kommet fram til at det ikke er behov for ytterligere hjelp.

Noter

**Q64** **Ny kontakt**

Når intervjuet avsluttes, spør intervjueren om det er i orden at vi kontakter igjen om ca 6 måneder for nytt intervju.

Ja ........................................ ☐ 1
Nei ........................................ ☐ 2

## Avslutning av intervjuet

***Til intervjueren:***

**Gi foreldrene god tid til å avslutte intervjuet eller kommentere. Kanskje er det ting de ønsker du skulle har spurt om eller annet de ønsker å formidle tilbake til oss. Dersom familien trenger tid til å avslutte, vis respekt for det. Hjelp til med eventuelle emosjonelle reaksjoner som de trenger hjelp til. Husk å takke for at de har deltatt og minn dem på at all kontaktinformasjon står i informasjonsskrivet.**

# FREKVENSRANGERINGSARK

HVOR OFTE ELLER HVOR MYE AV TIDEN DEN SISTE MÅNEDEN, DET VIL SI ____________________,

OPPLEVER DU PROBLEMET?

**1**

**ALDRI**

| S | M | T | O | T | F | L |
|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |

*aldri*

**2**

**SJELDEN**

| S | M | T | O | T | F | L |
|---|---|---|---|---|---|---|
|  | X |  |  |  |  |  |
|  |  |  |  |  |  |  |
|  |  |  |  |  | X |  |
|  |  |  |  |  |  |  |

*2 ganger i måneden*

**3**

**NOEN GANGER**

| S | M | T | O | T | F | L |
|---|---|---|---|---|---|---|
|  |  | X |  |  | X |  |
|  |  | X |  |  |  |  |
|  |  |  | X |  |  |  |
|  |  | X |  | X |  |  |

*1-2 ganger i uken*

**4**

**OFTE**

| S | M | T | O | T | F | L |
|---|---|---|---|---|---|---|
|  | X |  | X |  | X |  |
| X |  | X |  |  |  |  |
|  | X |  | X |  | X |  |
| X | X |  |  |  |  |  |

*2-3 ganger i uken*

**5**

**NESTEN ALLTID**

| S | M | T | O | T | F | L |
|---|---|---|---|---|---|---|
| X | X | X | X | X | X | X |
|  | X | X | X | X |  |  |
|  | X | X |  | X | X |  |
| X | X | X | X | X | X | X |

*4 ganger i uken eller mer*

*For mer informasjon om rettigheter og eventuelle oppdateringer av oversettelse, kontakt Grete Dyb, NKVTS.*

## Samtykke fra foreldre

Jeg, ………………………………….. (Forelders navn i blokkbokstaver), er villig til å delta i studien.

Jeg samtykker i at resultatene mine kan settes sammen med opplysninger om meg i offentlige registre (se infoboks nedenfor).

JA _____ NEI _____

Hva er registerdata?

I denne studien ønsker vi å innhente informasjon fra offentlige registre, for eksempel sykdomsregistre basert på opplysninger fra sykehus og primærhelsetjeneste. Det kan også være registre som gjelder inntekt, utdanning og yrke. Aktuelle registre er Norsk pasientregister, Reseptregisteret og registre ved Statistisk sentralbyrå. Navn og personnummer blir ikke lagret sammen med disse opplysningene. All informasjon vil bli behandlet med respekt for personvern og privatliv, og i samsvar med lover og forskrifter. Dersom du ikke ønsker at slik informasjon innhentes kan du reservere deg mot dette og likevel delta i studien.

Vi har ikke planlagt flere undersøkelser, men dersom det skulle bli aktuelt å igangsette en ny runde på et senere tidspunkt, samtykker jeg i å bli kontaktet igjen innen 5 år for et nytt intervju. JA _____ NEI _____

Dato: ___________________ Signatur forelder: ______________________________________________

**FORTSETTER PÅ NESTE SIDE**

(Denne siden oppbevares sammen med samtykkeerklæringen og separat fra resten av intervjuet og skal ikke påføres id-kode.)

**Kontaktinformasjon**

Navn forelder: ____________________________________________

Forelder fødselsnummer (11 siffer): ______________________________

Adresse forelder: __________________________________________

Telefonnummer forelder: ____________________________________

Navn barn: ______________________________________________

Barn født: _______________________________________________

*(Hvis foreldrene hadde flere barn på Utøya under terrorangrepet, skriv opp alle barnas navn og fødselsdatoer):*

__________________________________________________________

*Hvis en forelder ikke ble intervjuet trengs kontaktinformasjon så de kan få tilsendt spørreskjema*: Navn og adresse på forelder som ikke var tilstede:

__________________________________________________________

__________________________________________________________

**FYLLES UT AV INTERVJUER**

Dato for intervju: __________________________________________

Navn på intervjuer: _________________________________________