The psychosocial follow-up after the terror of July 22nd 2011 as experienced by the bereaved

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The large majority of parents and siblings were satisfied with the help they received from the public support services following the Utøya terror attack, but they also have advice for the support systems, according to this survey study by Kari Dyregrov and colleagues.

BY: Kari Dyregrov, Pål Kristensen, Iren Johnsen and Atle Dyregrov

The terror attacks on the Norwegian governmental buildings in Oslo and on the island of Utøya on 22nd July 2011 killed 77 persons, and represented a national tragedy that affected the whole of Norwegian society. Most of the deceased (69), mainly very young people, were brutally killed on Utøya. Here, the perpetrator attacked 500-600 young people participating in the Norwegian Labor Party's youth camp.

The ultraconservative and anti-Islamic terrorist pursued the teenagers on the island for more than an hour, and all of the killings took place between the hours of 5:09 and 6:33 p.m. The youths attempted to hide as best they could, but he hunted them around the island, and shot them in hiding places and during their flight, including some as they tried to swim to safety. The wounded who played dead were killed when the terrorist checked his victims for vital signs. During the shooting, many of the desperate and later murdered youths were in contact with their shocked parents or siblings on mobile phones. Their despairing family members tried to comfort or advise them to flee from the terrorist, before they eventually lost contact with them.

The killings on Utøya meant that about 210 parents and siblings lost a child or a sibling. In addition, some lost their partners or parents, and many adolescents lost a close friend.

Consequences of unnatural and violent deaths.
International studies show a high prevalence of anxiety, depression, trauma reactions and complicated grief in bereaved after terror events (Neria et al., 2007; Norris, 2007; Pfefferbaum et al., 1999). Like other unnatural deaths, such as accidents, sudden child deaths and suicide, for which preparations cannot be made (Barry, Kasl, & Prigerson, 2002), inflicted and violent deaths produce an increased prevalence of complicated grief in the bereaved (Keesee, Currier, & Neimeyer, 2008). In addition, strong, enduring bonds to the deceased, as well as the inability to find further meaning in life, increase the risk of a complicated grief process

(Boehlen, Stroebe, Schut, & Zijerveld, 2006; Keesee et al., 2008). A lack of meaning in life can be strongly experienced in the bereaved after such potentially traumatizing deaths and lead to suicidal thoughts (Stroebe, Stroebe, & Abakoumkin, 2005).

The Norwegian nationwide *Support and Care Study* on bereaved parents and siblings after sudden infant death syndrome (SIDS), accidents and suicide from 1997 to 2003 (Dyregrov, K., 2003; Dyregrov, K., Nordanger, & Dyregrov, A., 2000) and subsequent studies on bereavement by potentially traumatizing deaths show that such losses may cause extensive and enduring trauma and grief issues, followed by reduced life quality and reduced work and school functioning (Dyregrov, A., 2004; Kristensen, Weisæth, & Heir, 2009; Kristensen, Weisæth, Hussain, & Heir, 2014). In a large cohort study of more than 20,000 parents, a Danish research group (Li, Precht, Mortensen, & Olson, 2003) documented a greater risk of early death and other negative health consequences among the bereaved after unnatural deaths than after natural deaths. To the bereaved, their age, proximity to the event and to the deceased, the quality of family interaction, and support from support systems, workplace, school and social networks, are of great significance for the development of psychopathology in the aftermath of terror (Norris et al., 2002).

Bereaved parents (n = 67) and siblings (n = 36) after the terror killings on Utøya of 22nd July 2011 had a high prevalence of complicated grief reactions (82% vs. 75%), post-traumatic stress reactions (63% vs. 72%) and general psychological distress (88% vs. 75%) one-and-a-half years after the mass killings. There were significant gender differences (women most affected), and the losses had a substantial negative influence on work and school functioning in parents and siblings (Dyregrov, K., Dyregrov, A., & Kristensen, 2014b).

Help requested after unnatural deaths.
In previous Norwegian studies, the bereaved have expressed a need for help, both from the support systems (professionals/health and social care agencies, police, religious communities, etc.), social networks and peers (Dyregrov, K., 2002; Dyregrov, K. et al., 2000; Dyregrov, K., Berntsen, & Silviken, 2014), as international studies (McMenamy, Jordan, & Mitchell, 2008; Wilson & Clark, 2005), have also documented. The bereaved have emphasized the need for assistance from all three groups, as they provide different forms of help and fulfil different needs.

The results of the *Support and Care Study* showed that the public support measures from, for instance, therapists, doctors, home care and nurses varied in quality and quantity in Norway (Dyregrov, K., 2002; Dyregrov, K., Dyregrov, A., & Nordanger, 1999; Dyregrov, K. et al., 2000). When the bereaved in the *Support and Care Study* were asked to describe ideal public help, they highlighted systems that secured automatic contact from a professional team, and also emphasized: immediate outreaching help from qualified personnel; information about the event/what happened and reactions that may occur; assistance for bereaved children; and the opportunity to meet others that have experienced a similar situation. Based on the fact that many isolated themselves or did not have the energy to seek help, they asked for an active and outreaching support system. Already in the 1997 study, the

bereaved emphasized that in case they declined help shortly after the traumatic loss, the offer of help should be repeated respectfully over time. Furthermore, they wanted stability and continuity from competent helpers, and they wanted help that was flexible, needs related and individually adapted, and help that lasted over time (Dyregrov, K. & Dyregrov, A., 2008; Dyregrov, K. et al., 2000). Those bereaved after the tsunami in South-East Asia in 2004 also requested proactivity in the support services (Hjemdal, 2007).

Recently, the *Support and Care Study* was replicated for the bereaved after murder, suicide, sudden child death, and accidents in the indigenous population in Sámi areas in Norway. While the results of the study showed several similarities, both in terms of reactions to traumatic losses and experiences with the public support system, we also found some differences related to contextual factors and ethnicity (Dyregrov, K. et al., 2014b). An interesting finding was that the strong norm in the Sámi culture of caring for themselves (*Iés bierget*) with the help of the extended family did not work because the strains of the unnatural deaths on the families were heavier than any other they had experienced. Thus, a central finding in the article was that this norm, together with a taboo on seeking a psychologist and the experience of the same organizational weaknesses in the support systems that the bereaved after the 2011 terror attacks experienced, acted as a barrier to adequate and necessary follow-up in the Sámi population.

Public help after the 2011 terror attacks.
There has been a gradually increasing understanding among professionals and authorities that those bereaved by unnatural deaths will need more attention and help than previously assumed. After the 2011 terror attacks, the health authorities instructed the municipalities to give proactive follow-up to the affected. The proactive follow-up model is based on the values of the Norwegian welfare society, through the universal principle of right to health care, an emphasis on preventive health care, and user involvement. The local communities were asked to give proactive follow-up, which meant that the helpers initiated contact with the closely bereaved. Everyone, including the survivors, should have a permanent contact person, and continuity of contact through a follow-up period of at least one year. It was recommended that there should be frequent contact during the initial period, for example weekly, which is then adapted to individual needs. The contact person should have a health care or social/educational background, and provide personalized practical assistance and concrete support (Report IS-1984E, 2011).

In addition to the help offered from the local communities, the most closely bereaved were offered four weekend gatherings close to the municipality of Oslo by the Norwegian Directorate of Health. The professional content was developed and directed by the Center for Crisis Psychology, and conducted in collaboration with Norwegian institutions working with grief. A separate article reviews this assistance measure and is therefore not discussed in this article (Dyregrov, A., Dyregrov, K., Straume, & Grønvold Bugge, 2014). In addition, the Norwegian Directorate for Education and Training actively used Norwegian academic communities so that educational institutions could meet pupils and students in a proactive way (Schultz,

Langballe, & Raundalen, 2014).

User involvement and user perspective in research.
Through the recognition that users and patients have unique, experiential user knowledge of their own lives, sufferings and use of services, the law on health and care services (Prop. 91 L, 2010–2011) specifies that, «Increased user involvement is an instrument for reaching the coordination reform's aims of better coordinated services». In the Health Directory's report on «User involvement in the mental health field» (IS-1315, 2006), a user is defined as «a person who makes use of relevant services in one form or another», user involvement as «the users' influence on the development of services», and it is established that «user involvement implies that the public services utilize the users' experience and knowledge to provide the best possible help».

The report also specifies that «User involvement is a *statutory right*, and hence not an issue that the service providers may choose to deal with or not». It is also a *tool* on several levels. For instance, user involvement may contribute to increased «accuracy» in the design and implementation of both general and individual services. The aim is satisfactory user involvement at individual levels, system levels (e.g., user experiences, user surveys), and political levels.

The users' needs and experiences with help provisions are the best guarantee in securing quality and sufficient services. This is an important backdrop for our research project on bereavement after the terror attacks of 22nd July 2011. In addition, our clinical experience and previous research on bereavement by isolated, potentially traumatizing unnatural deaths indicated that there could be a great need for help after the terror attacks of 22nd July. To build on previous knowledge, create new user knowledge, and possibly assist the bereaved further in the wake of the terror attack, a comprehensive study was initiated by the Center for Crisis Psychology. The study examines several issues.

Aims and research questions.
The aim of this article is to provide a phenomenological description and interpretation of the public help as experienced by parents and siblings 18 months after the terror at Utøya. The research questions are based on the bereaved persons' reports of needs and offers of help, whether they had missed any form of help, whether they had experienced any form of help as a strain, and their satisfaction with and advice for the support systems:

1. What public support services were offered to the bereaved after the terror attacks on 22nd July 2011?
2. Does the offer meet (a) the guidelines in the proactive model and (b) the needs of the bereaved?
3. Should anything be improved?
4. What advice would those bereaved after the terror attacks on 22nd July 2011 give to the support services?

Methods

Through a longitudinal, non-experimental design with three measurements (18, 28, and 40 months after the terror attacks), the situation of the closely bereaved will be studied, focusing on various conditions that can worsen (experiences from the event, previous psychopathology, pressure from the media, trial, etc.) or improve (help from public support services and social networks, etc.) their situation (Dyregrov, K., Dyregrov, A., & Kristensen, 2014b).

While questionnaires with closed and open questions are used at all points of time, in-depth interviews with a subsample are used at 28 months. A central topic is how the need for help of the bereaved is met by the public support services. This is the topic of this article.

Procedure. As the majority of those killed on Utøya were underage and had caregivers who were both biological parents and stepparents, both groups were invited to participate in the project, regardless of whether they had lived with the deceased at the time of death or not. This also applied to biological siblings and half- or stepsiblings, and partners and children of the deceased. The names of biological family members were obtained through a link between public lists of names of deceased and information from the National Population Register. As step-relations are not specified in the National Population Register, these were recruited through biological parents, and thus exclude an overview of the total population of (step)parents and (half-/step)siblings. In total, the families of 67 of the 69 killed were invited to participate in the projects, as two of the deceased and their families were not Norwegian citizens and not residents of Norway. In addition, close friends of the deceased were invited to participate through parents and siblings.

The study emphasized a gentle approach, based on principles we had previously developed for research on vulnerable populations (Dyregrov, K., 2004a; Omerov, Steineck, Dyregrov, Runeson, & Nyberg, 2013). The different groups of bereaved people received written letters of information with a consent form, which they returned before they were sent the questionnaires, either by email or for completion via SurveyMonkey (a tool for surveys on the Internet). For siblings without competence to consent (12-16 years), parents consented on their behalf. The study is approved by the Regional Committee for Medical Research Ethics.

Sample. At T1 (after 18 months), 67 parents and 36 siblings participated. Demographic and loss-related variables for the parent and sibling sub-samples are presented in Table 1.

TABLE 1: Demographic and loss-related variables of bereaved parents and siblings after the terror attack of July 22nd 2011.

	Parents, *n* = 67	**Siblings, *n* = 36**

		Parents, *n* = 67	Siblings, *n* = 36
AGE (*M*, *Range*, *SD*)	Women	51 (40–78) (6.85)	23 (12–44) (8.14)
	Men	52 (39–66) (6.29)	21 (12–38) (8.18)
GENDER	Women	37 (55%)	28 (78%)
	Men	30 (45%)	8 (22%)
RELATION	Mothers/sisters	37 (55%)	28 (78%)
	Fathers/brothers	30 (45%)	8 (22%)
PLACE OF LIVING	Urban	38 (57%)	16 (44%)
	Rural	29 (43%)	20 (56%)
AGE OF DISEASED (*M*, *Range*, *SD*)		21 (15–51) (7.30)	17 (15–19) (1.15)

The parent sample consisted mainly of biological mothers (95%) and fathers (83%), and thus only a minority of stepparents. While 43% had completed less than 12 years of schooling, the majority (57%) had college or university education. Most of the parents (88%) were married or cohabiting, while 3% were widows/widowers and 9% were single parents.

The sibling sample consisted mainly of biological sisters and brothers, and only 8% were stepsiblings. Among the siblings, 44% were in lower or upper secondary school, while 17% studied at college or university. The remaining siblings (39%) were working.

A total of 48 (72%) of the 67 deceased were represented by one or more parents, and 33 (50%) of 66 deceased were represented by one or more siblings. One of the deceased did not have siblings. While 48% of the parents had lost underage children (*M* = 16 years; *R* = 15-17 years), 52% had lost children over the age of 18 (*M* = 21; *R* = 18-51 years). There were no significant differences in age or gender in the biological parents and siblings who participated, compared to the families of the 19 deceased who did not participate.

Questionnaire. The bereaved filled out a comprehensive questionnaire with standardized instruments (trauma reactions, complicated grief reactions, psychological distress, work/school and social adaptation, ruminative style, the reception of social support) and different questions related to background and social demography, changes in social relationships, external stressors (media and trial), and previous stresses. In addition, the bereaved responded to questions on public offers help and support measures, which is what will be reported in this article.

The bereaved were presented with the following questions: (a) Have you felt the need for help from professionals/the support services after the death? (b) Have you received help from any professionals/support systems after the death? (c) Are there any professionals/institutions that you have missed help from? (d) How was the

contact with the professionals established? (e) Are you satisfied with the help from professionals? One question was a combination of a standardized and an open question, where after ticking off the standardized question they were asked to describe their answer as follows: (f) Has the contact with any of the professionals been experienced as stressful? The bereaved were also asked to qualitatively answer the questions: (g) Has anything prevented you from receiving support or help? and (h) Can you give some advice to professionals on what kind of help the bereaved in your situation are in need of?

Data preparation and analysis. Bereaved parents and siblings were given the choice between answering the questions on paper (37% vs. 63%) or digitally on SurveyMonkey (53% vs. 47%). The standardized questions were processed in SPSS, while the qualitative answers were transferred to Excel format.

For this article, simple descriptive analyses of data from the questionnaire were conducted to describe the support services given to parents and siblings. Their detailed descriptions of the measures are analysed through qualitative thematic analysis (cf. Braun & Clarke, 2006). Such analyses involve (a) a thorough read-through of all significant units (written statements), (b) grouping of statements with similar content, (c) naming of the groups (categories), and (d) a grouping of categories to named, overarching themes.

The qualitative analyses were first conducted by the first author (a sociologist), and then altered in accordance to consensus discussions with the co-authors (psychologists and a sociologist). In the results section, quantitative and qualitative analyses are presented together with selected quotes from the qualitative material. Thus, the results are based on theory, researcher and method triangulation (Kvale, 1996).

Results

What kind of help have the bereaved received?

Table 2 shows how the answers from parents and siblings were distributed in the different standardized questions on help and support services 18 months (T1) after the terror attacks.

TABLE 2: Psychosocial help and support for bereaved parents (*n* = 67) and siblings (*n* = 36) 1½ year* after the terror attack July 22nd 2011. (*T1 = 1½ year after July 22nd 2011.)

	Parents N (%)	Siblings N (%)

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Need for help from the support systems – to a large / fairly high degree – to some degree – to a little degree / not at all	46 (69%) 15 (22%) 6 (9%)	23 (68%) 3 (9%) 8 (24%)
Yes, has received help from the support systems – previously – still	63 (94%) 23 (34%) 40 (60%)	35 (97%) 20 (56%) 15 (42%)
Yes, has received help from – crisis team / contact person – psychologist / psychiatrist – GP / medical doctor – police – family councellor – teacher / school	45 (67%) 44 (66%) 51 (76%) 20 (30%) 7 (10%) –	16 (44%) 23 (64%) 9 25%) 4 (11%) – 15 (42%)
Contact establishment to help – I was contacted – I contacted myself – others made contact for me	30 (49%) 16 (26%) 15 (25%)	11 (31%) 8 (23%) 16 (46%)
Yes, I have missed help from – crisis team / contact person – psychologist / psychiatrist – GP / medical doctor – police – family councellor – teacher / school	4 (6%) 7 (10%) 4 (6%) 6 (9%) –	4 ;(11%) 2 (6%) 2 (6%) 1 (3%) 5(14%)
Yes, I have experienced contact with some helpers as stressful	15 (25%)	10 (29%)
Satisfied with help from professionals – to a large / fairly high degree – to some degree – to a little degree / not at all	4 (73%) 15 (24%) 2 (3%)	25 (74%) 8 (24%) 1 (3%)

Both parents and siblings reported a great need for help one-and-a-half years after the killings. Only 9% of the parents and 24% of the siblings experienced needing little help from the support services. In the period up to T1, almost all parents (94%) and siblings (97%) had received help from the support services. They had received help from several different groups of professionals, and the parents reported contact with most of the groups. Approximately 2/3 of the parents and half of the siblings had

been in contact with a crisis team or contact persons after 22nd July 2011. While half of the parents reported that they had been contacted by the team/contact person, about 1/3 of the siblings reported the same. Parents (51%) and siblings (69%) who were not contacted by a crisis team or contact persons either made contact themselves, or others made the contact for them.

Psychologists/psychiatrists and the regular general practitioner were the professional groups with which most parents and siblings had been in contact after the terror attacks. Few of the parents reported that they lacked help for the children in their family. Many of the parents (76%) but not as many siblings (25%) had received help from their regular general practitioner. While one out of 10 parents reported having received help from a family counsellor, 42% of the children stated that they had received help from their school.

A small minority of the bereaved felt they had lacked help in the period after the 2011 terror attack. The most relevant are displayed in Table 2. Although psychologists/psychiatrists and regular general practitioners were the professional groups that most of the bereaved had received help from, these were also the groups that most of the bereaved felt there was a lack of contact with. Most of all, siblings were missing help from their school (14%). On the question of whether contact with any professionals had been experienced as a strain, one out of four confirmed this. These strains are described in the qualitative results chapter. On the question of satisfaction with the public support services, 3/4 of the parents and siblings stated that to a large extent or a fairly large extent they are satisfied with the help received from professionals (Table 2).

Results from qualitative accounts.

Presented below are the bereaved persons' elaborations as to why they experienced parts of the public support services as straining, and what may have prevented them from receiving help, before they provide their advice to professionals on what the bereaved in the same situation are in need of. The main themes from the analysis are summarized in a model (Figure 1).

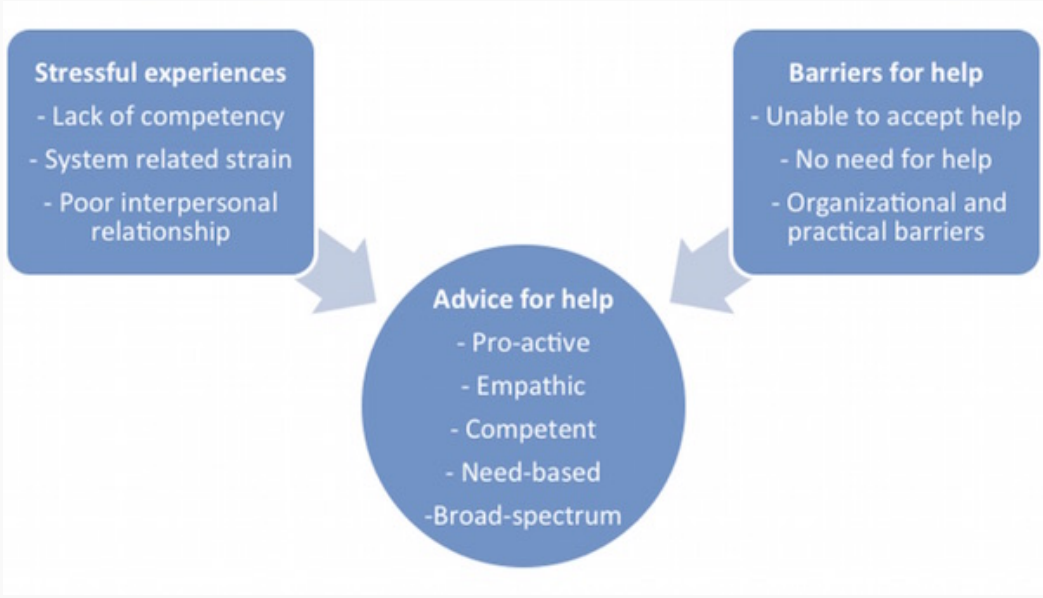

FIGURE 1: A model over stressful experiences of public support services, barriers for accepting help, and advice for help, as seen by the bereaved.

Straining aspects of support. The question was responded to by 16 (24%) parents and eight (22%) siblings, and the descriptions were grouped into the following themes: lack of understanding/competence, system-related strains, and «lack of chemistry» in the contact with helpers.

It was experienced as difficult that not all helpers expressed an understanding of the situation, how the event affected the bereaved, and thus, what help they needed. Some had the impression that the helpers were more steered by the textbook than the person they had in front of them. The frequent reminder to «take a break» and the telling of stories of others who had moved on earlier, without attempting to determine what needs for support the bereaved had, was experienced as insensitive. Another difficult experience was that some helpers were more preoccupied with establishing a diagnosis and talking about specific topics than with linking the conversations to what was relevant for the individual.

Experiences of strain were also linked to information that the bereaved experienced as intrusive, either because the timing or the content did not make sense; for example: «a rather too outspoken police officer who in the shock phase was a bit too insistent on offering to show pictures from the site and of the deceased», or priests at Sundvollen[1] who «were ready to talk about life, death, and God». Distrust regarding the need for sick leave was also mentioned as straining. Others had experienced helpers who expressed sympathy, but who did not give feedback that was useful to the bereaved. One parent:

> *My psychiatric nurse just sighed and asked questions. Until June (after 8 months of contact), she did not give me any feedback. I also had the feeling that I inflicted my difficult thoughts upon her, and had a bad conscience every time I left.*

System-related strains included a lack of continuity when the help or contact initiated with helpers stopped for various reasons. This meant that one had to deal with many different helpers who tended to «explain things over and over again». Others found it distressing to be sent back and forth when appointments were changed or cancelled. It was also experienced as straining to have to fight a rigid system to secure help for all family members, for example in case of step-relationships and non-biological relationships, or when the bereaved stayed at a residential address outside the parental home in the immediate period after the terror. Some pointed out that the crisis teams did not work proactively, as had been envisioned.

The bereaved described a «lack of chemistry» with several professionals and assistance institutions as straining, which led to some withdrawal from the help measures. This applied to siblings to a greater extent than parents. No groups of professionals were more frequently mentioned than others; instead, crisis teams, psychiatric nurses, lawyers, priests, police, psychologists, physicians/psychiatrists and family welfare centres were all mentioned. The «lack of chemistry» could be related to a condescending attitude, a lack of interest, or a «know-it-all attitude, with a desire to show it».

Barriers to receiving help. The question was responded to by 27 (40%) parents and nine (25%) siblings. The descriptions were grouped into these themes: not able to receive help, did not think they needed help, and organizational and practical barriers.

In particular, bereaved parents reported various obstacles in receiving help for reasons of their own. They described that «it became too intense», «they lacked the energy», «did not manage», or «felt the need to withdraw and be alone», and that they «sometimes were too mentally exhausted to manage to receive help». One parent described how the strong need for help in itself was an obstacle: «When the heaviest moments arrive and last over time, I want to seek help, but I don't have the strength to do it myself». Others described a fear of losing control: «I have felt that I have been in a bubble, and it has been difficult letting anyone in. I have been scared of losing the control», and distrust in the helper and the help as obstacles for support:

> *I, myself, have held back the need for help from, among others, a psychologist because of everything that emerged in the media regarding the offender and the diagnosis that was set there. This led to me having little faith in the system, and did not see the need for seeking help.*

Different organizational and practical barriers were described by both parents and siblings. This included situations where the bereaved could not receive help because they did not have the economic resources to miss work, where geographic distances to the help were too long, where the bereaved where in prison, where they were not receiving help outside their own municipality because they were living with

the rest of the family in another, where participation in support group work resulted in them not being able to prioritize themselves, or where a focus on bereaved children was prioritized. One sibling expressed how the time factor was an obstacle to help one-and-a-half years after the terror: «Now that some have forgotten, you get little understanding of the need for help and facilitation». Another sibling described how a cumbersome bureaucracy could be an obstacle to help for students:

> *A cumbersome bureaucracy, ref. the Norwegian State Educational Loan Fund. Small amounts that almost don't pay off compared to the time you spend on calling, emailing, and nagging. Little proactive offering, and even less help to apply.*

Advice to professionals on helping the bereaved. This question received the greatest response of all the open questions, and was elaborated on by 51 (76%) parents and 30 (83%) siblings. Their numerous pieces of advice to the support system were analysed, and distributed into these main themes: A proactive support service, empathic and competent help, and user-adaption and a broad spectrum of help. Support at school and work is given its own theme.

A proactive support system. Many parents in particular, but siblings as well, were occupied with how the help should be organized in order to let the person struck by crisis make use of the help measures. Some begin their account by establishing that even though the need of help is individual, an extreme event such as the killings on Utøya requires «an available support system», and one needs «follow-up, follow-up, follow-up». Much of what concerns the organization of help is included in the proactive model. While some relate their advice to their own positive experiences of being met proactively, others base their advice on not being met this way. The advices are still strongly concurrent.

Firstly, the bereaved point out that helpers need to *make contact and offer help*, because, as one parent states: «Don't expect that those who are in a completely absurd situation will make contact by themselves». To support this strong advice, the bereaved give the reason that they do not have the energy to make contact themselves, and that they are not aware of what help measures they need or whom they can turn to. The following quote summarizes what many communicated in their comments: «Most importantly, a conversation with a professional should NEVER end with: 'if you need help, just call'». Professionals need to *repeat the contact* if the bereaved turn down their offers to begin with, as, in the beginning, the bereaved person is overwhelmed and in shock, and thus it is not the case that «a no after two days means no for ever». Why the offer of help needs to be repeated over time is explained like this: «After a message such as we received, we are destroyed by grief, and time will pass before we realize that we need help». The bereaved also wish for frequent contact from helpers, so that they can check on them and how they are doing over time, especially if they have turned down an offer of help. Feeling secure that «everything is normal» is stated as important in the insecure everyday

life that many experience after such an event.

Many point out the importance of being given a *contact person* who can be available as long as the family needs them, and that takes initiative. With this contact, possibly represented by the regular general practitioner, the bereaved person could have regular meetings, for example monthly. Some give the advice that the contact person can make home visits «to see and hear how we are doing». Both parents and siblings point out that the follow-up needs to continue *over time*; one parent, for example, expressed it thus: «Don't let me go, even though I seem okay – this takes time». Many express how helpers need to have a wider time perspective on the need for help than they seem to have; which means that every conversation needs time and that one must have the right to help «a long time after such traumas». One parent gives the reason that the killings on Utøya «had so many facets» (the sudden loss, the scale of the atrocity, the loss of a child, and everything that never is to be, stories from the friends of the deceased, the young being killed because of their democratic engagement, the police who arrived too late, the commission report, and the trial), and that after one-and-a-half years, colleagues, friends, and even most of the family are preoccupied by completely different things to the mourning of the bereaved. The right to receive sick allowances should, therefore, according to another parent, also extend to over one year.

Some point out the importance of the support system facilitating special circumstances in the situation of the bereaved, for example securing the right of inmates in prison to take part in the grieving in a natural way together with family, friends and other bereaved. Stepparents point out the importance of being included in the offers from the support systems on the same levels as biological parents when stepparents have been caretakers of, or had close contact with, the deceased.

One parent summarizes the central message regarding the organization of professional help:

> *Be on the supply-side, and never say «Call if you need anything, we are here». I did not know what I needed, and there is a VERY high threshold to make that call. Take contact and follow up.*

Empathic and competent help. For almost all parents and siblings, it is necessary that the help is communicated with understanding, that is, both empathic and competent.

Empathy seems to be of great importance, both to young and older bereaved. One needs to be seen and heard, to be shown consideration with sensitivity and respect. It is important that one's feelings are taken seriously, and «that professionals take the time to listen properly to what people who have found themselves in such a situation have to tell; not condescending conversations». In the extreme situation they find themselves in after such an event, they say that they need to feel that someone cares. They express how this provides essential security in a situation where the world is suddenly turned upside down. The bereaved also ask for

«recognition that their shock, pain and grief take a much longer time than in a 'normal' death and especially to young people experiencing grief».

Competence. The wish of the bereaved for «understanding» implies that the help should be based on the understanding of grief and trauma in professionals. They point out the importance of professionals having the knowledge to understand what stresses they have been exposed to, and that it leads to decreased attention, decreased energy, and that one needs «to have it confirmed that one is not crazy or that one will not simply die of grief». One needs support from empathic and competent professionals «to dare to feel the unbearable pain». As this parent points out, there is a wish for direct and knowledge-based responses: «Many professionals beat around the bush and say, yes, yes, completely normal, and so on… they need to be a bit more direct». Another parent supplements this image: «Something that has recurred is: 'Tell us if there's anything we can do' – what we can often feel the need for is for someone to help us make decisions… concrete offers, instead of leaving it to us». In addition, they wish for professionals to have knowledge of the time perspective of grief, so that «one doesn't need to expect much of a result in the first six months», and wish to continue receiving help when others withdraw.

The accessibility of an empathic and competent helper over time works as «Valium» according to one parent:

> *You need someone who can be there when you need it. My psychologist is my «Valium». I can call her any time, but have only done it twice during these 19 months. Just knowing that she will be there on the phone if I think I am going to «lose my mind», has been my «Valium». I have had very good connection and dialogue with my psychologist.*

Needs-adapted and broad-spectrum help. Both parents and siblings point out the importance of everyone receiving help that is adapted to their and their family's specific situation, and mention many forms of help that they consider important. They ask for early and clear information that is repeated, and a helper who listens to the bereaved person's thoughts and talks about that which is painful and difficult. A parent elaborates this as follows: «One needs to talk about everything that happened and find ways to close the event. For me, it was a jigsaw that I rebuilt over and over, and in the end I could put it in an invisible box». In addition to focusing on the event, conversations about the deceased are central. The bereaved wish for help to handle the loss and at the same time live an approximately normal life, as expressed by one parent: «… I don't wish to forget the person who is gone, but to be able to live with the grief and the loss in a positive way». Further, the bereaved mention the importance of normalizing strong and unusual reactions, and receiving help to express anger.

The bereaved also mention the importance of receiving support for having «time off from the grief», and being allowed to laugh and remember everything that was

good, and express the importance of learning strategies for self-coping in order to «regain the control» and «take care of oneself». One parent talks about «cultural differences» when she points out the importance of having a support system that also attends to spiritual dimensions: «Ask if the person believes in anything, and perhaps also start a spiritual treatment, because some will be helped by professionals, others through spirituality». Many claim that there should be a greater focus on giving practical help in the home, as in the beginning «we need help for everything», and as «a clean and tidy home and good food in your stomach remedies your mood». Organized peer support, as given at the gatherings in Gardermoen, are also brought up as very valuable. While the young mostly refer to the help from school and public health nurses, the elder more often mention psychologists and the regular general practitioner as central helpers.

Advice specifically for school and work. Almost all siblings comment on the need for help from school, and this is especially mentioned as it is linked to a separate and specific context. The young make clear that the help needs to be specifically adapted to each individual and his/her needs, and most advice concerns how the help should be organized and arranged, and what kind of help is important. Like the parents, some of the siblings give advice based on what they missed, while others give advice based on good experiences with the help that they recommend – and both groups point to the same issues.

The siblings express that it is necessary for normal school progression that students struck by crisis experience «an opportunity for understanding that one needs adapted education and a reduced programme for a period of time». One must be offered individual adaptation from the school, and should not have to ask for it. It may be «difficult to ask for adaptation, especially when the teachers have expressed a lack of understanding». The youngsters recommend that one needs to receive «close attention from the beginning». They also propose that the school «needs to follow up after a few months and see how it is going», and give «follow-up over a longer period of time».

Siblings strongly indicate that teachers need to show that they «see the bereaved», that they «care», have «understanding for the situation», and «take the feelings of the bereaved seriously». How the teachers may express that care is specified by this sibling: «The students need to know that the teachers are watching you, and asking you sometimes!» Another sibling writes that it is «important to be shown consideration, because your memory is poor and is easily distracted». Thus, the teachers need to spend more time on the student than previously, as the schoolwork is harder than before. Several siblings point out that it is «important to the one struck by crisis to have security and predictability, and understanding of reduced concentration and reduced ‘energy’». More competence in relation to grief and «understanding the nature of grief» is also requested: «There should be awareness of what someone in such a situation actually goes through, about reactions and grief. That the person is no longer the same, and never will be».

Several of the young people mention that it may be useful to have an adult, such as a public health nurse or a consultant in the school system, on whom one relies and

to whom one can talk if something feels difficult; as one sibling expressed it: «See if the person is having a bad day, and if so, talk to him». The adaptation of education should emphasize flexibility, and be discussed in consultation with the student/home. The school needs to adapt its teaching to where the student is, and not increase the pressure on the young person by, for instance, numerous tests or short deadlines on assignments. Adapted work tasks may further involve flexibility with regard to registration/deregistration for exams.

Young people who were in a work situation point out that it is «important that one return to the same, secure job that one had, and not have to learn a new job in the middle of the catastrophe». It is important that the employers show understanding and respect for the employee who struggles, and creates «an adapted programme for the person on sick leave». One youth summarizes the importance of support from school and work when struck by crisis:

It actually takes a very long time before one can perform as one previously could, perhaps you never get to that level again. I'm not there yet. Still become tired and unfocused faster than before. It is important that those who have students/employees know this and accept it, and don't expect you to be back at a hundred percent after a while, even though you apparently look like you are. Higher headroom has to be allowed for blunders and more long-term follow-up.

Discussion

Follow-up in the right direction, as seen by the users.
One-and-a-half years after the killings on Utøya, almost all bereaved parents and siblings report that they have received help from professionals and support systems. Compared to previous Norwegian studies, the bereaved after the 2011 terror attack express an even greater need for help and have been given more comprehensive and proactive support services than those bereaved by violent deaths that have occurred separately (Dyregrov, K., 2002; Dyregrov, K. et al., 2000; Dyregrov, K. et al., 2014a). While in the *Support and Care Study* from 1997 and the study from Sámi areas from 2009, 49% and 54% respectively expressed «a great need for help»; 69% after the Utøya killings did the same. This, in addition to very few expressing no need for help at all, is probably because this particular group of bereaved people have been exposed to a loss followed by an extreme trauma, with subsequent strong and long-lasting reactions. Other parts of the study show that they probably have a somewhat delayed grieving process, as the private grief was «put on hold» by the long-lasting external «noise» of the trial and sentencing, commission work, and the immense media focus (Dyregrov, K. et al., 2014b). When the expectations of being helped in certain ways by a public help system is so strongly present, it may be due to the expectations of the Norwegian welfare state which are built up over time, and the proactive follow-up model that was indicated to the bereaved themselves after the terror (Report IS-1984E, 2011).

Although many of the bereaved in the studies from 1997 and 2009 received help

from professionals, even more report having received help in the present study (respectively, 85%, 79% and 95%). Furthermore, the bereaved after the terror on Utøya did to a large degree receive the proactive help that the health authorities recommended to the municipalities, and which those bereaved after traumatic deaths have previously asked for. This implies that crisis teams/municipalities more often initiated contact via a contact person, and that the bereaved received a more overall and broad-spectrum offer. A much greater proportion of the bereaved also received help from psychologists and regular general practitioners. While only 22% of parents who lost young children in suicide, accidents and SIDS received offers of help from psychologists in the 1997 study, 51% of the bereaved after Utøya received the same. Moreover, a much lower number of the present sample report that they were missing different forms of help compared to previous studies (Dyregrov, K., et al., 2000; Dyregrov, K. et al., 2014a). The young report that, after the 2011 terror attacks, they have received a little more help from school compared to previous studies after traumatic deaths in siblings (Dyregrov, K. & Dyregrov, A., 2008; Dyregrov, K. et al., 2000).

The explanations for the increased intervention may involve more than just the instructions given by the authorities to the helpers. We can presume that knowledge of the serious consequences that follow violent, unnatural death (Dyregrov, K., 2003; Kristensen, Weisæth, & Heir, 2012; Li et al., 2003; Neria et al., 2007) has gradually been disseminated. At the same time, the Norwegian welfare state has gradually built psychosocial preparedness in the municipalities, with a focus on crises and catastrophes. In addition, the debate on medicalization in crisis psychiatry and psychosocial crisis help is to a large extent closed (Dyregrov, K., 2004b), so that consensus has moved in the direction of professionals discussing only to a limited extent *whether* it is necessary to help after potentially traumatizing events, and to a greater extent discussing *how* that help should be, and what kind of help is needed. After the 2011 terror attacks, a strategy for follow-up was chosen that was closer to a prevention ideology than a treatment tradition. This implied that one now reached out to the bereaved at an early stage, to prevent health problems, rather than «wait and see» who becomes ill and needs treatment (Dyregrov, K., 2004b).

By using the satisfaction of the bereaved in the follow-up as a basis, we can establish from a user perspective that the help after the terror on Utøya took many steps in the right direction for the bereaved after potentially traumatizing deaths. The satisfaction with public help is much higher after the 2011 terror attacks than in comparable groups in previous studies; while 73% of the parents were satisfied to a «high» or «fairly high degree» with the help from professionals, the numbers were 34% and 33% in the 1997 and 2009 studies. There may be several explanations for the increased satisfaction with the follow-up by the help systems. First, it is likely that the help *has* improved. The «proactive» model for help that was instructed by the Norwegian Directorate of Health (Report IS-1984E, 2011) is highly consistent with very early recommendations from professionals within the field of crisis psychology (Dyregrov, A. & Ingebretsen, 1982), and what has been a unanimous demand in research on bereavement after single deaths (crises) (Dyregrov, K.,

2002; Dyregrov, K. et al., 2000; McMenamy et al., 2008; Wilson & Clark, 2005) and catastrophes (Henriksen, 2002; Hjemdal, 2007; Reme, Walstad, Harsem, Furre, & Henriksen, 2003). Helpers have to a much larger extent than before been active and *initiated* contact with the bereaved. Because of the nature of the catastrophe, one has also had an overview of all the involved families, and known who to contact, whereas in the case of single events there has been a barrier to getting in touch with all involved families (Dyregrov, K. et al., 1999; 2000). Several of the bereaved have had a contact person who has secured continuity and safety in the follow-up. Such a contact person was asked for by those bereaved after suicide, SIDS and accidents in the 1997 study, at a time when a proactive model was fairly unlikely (Dyregrov, K., 2004b; Dyregrov, K. et al., 2000).

A high degree of satisfaction with the help systems may also be related to the fact that many bereaved have received comprehensive and needs-related help, and that so many have received help from psychologists and regular general practitioners, which, in previous studies, have been the most requested types (Dyregrov, K. et al., 2000; Dyregrov, K., 2009). The help measures after 22nd July also seem to have reached the young, which, in previous studies, was clearly not the case, and is an important criterion for success in providing help to parents. While previous studies have also pointed to an overly early termination of the help measures (Dyregrov, K. et al., 2000), we can see that many helpers still stand by the bereaved after one-and-a-half years, even though the scale of the help shows a natural decrease.

Still not optimal help?

In light of the long-held knowledge about what the bereaved, in unison, ask for after potentially traumatizing deaths, we see that the proactive model for follow-up that has been used after the terror on 22nd July is well on the way to providing measures in line with this demand. Still, there are many indications that the help may still be improved. The bereaved themselves point to several circumstances which show that the support measures have for different reasons not been as good as required. The results show that many were not contacted by helpers, did not receive a contact person or the adapted help needed, or were not followed up for a sufficient time. These are circumstances that can be improved through an even stronger emphasis on routines and systems, and cooperation between crisis management, crisis teams, and professionals in the municipalities. The Norwegian Directorate of Health's *Guide to Psychosocial Measures in Case of Crises, Accidents, and Catastrophes*, which will be revised in 2015, will be a useful tool in such work.

Increased competence in the helper. It is perhaps more of a concern to an optimal support service that the bereaved in this study point to the same distressing conditions in the contact with the helper or the support systems as in previous studies (Dyregrov, K. et al., 2000; Dyregrov, K. et al., 2014a). In particular, «lack of understanding» is stated as a central strain. This involves both the helper's lack of empathy and their lack of understanding of the situation of the bereaved after a traumatic death. This probably contributes to many bereaved people, both young and old, not receiving the help they need and which could have been given. Professionals that demonstrate competence in meeting with a person affected by

crisis are very important to meeting the bereaved person's need for security, through creating predictability and giving back a feeling of control after «the world has turned upside down», and all one's basic assumptions about how and why things happen have been shattered (Janoff-Bulman, 1992).

Most professionals do not often meet bereaved people after unnatural, violent deaths, as fortunately they do not occur very often. The result is that many have little routine knowledge in meeting people struck by crisis, and much of the support process takes place as learning through «negotiations» and adaptations in the individual situation. As the parties' experience, interpretation, and evaluation of support measures will be related to the context in which they occur (Goldsmith, 2002), helpful support will be characterized by a mixture of successful use of routine knowledge and exploration and adaptations in the individual situation.

If well-intentioned professionals ask people in shock about what kind of help they need, quotations from the bereaved show that this is something they cannot answer. Knowledge, including knowledge about normal, immediate reactions and early psychological first aid in cases of crises and catastrophes, coping skills and grief and trauma therapy, is therefore essential in providing the helper with the «understanding» that many of the bereaved ask for. With a basis in knowledge about the situation of the bereaved, professionals can, to a higher degree, take control, and emphasize information and ease anxiety in a secure context (Dyregrov, A., 2002). A professional who expresses insight in what should be said and done has an important tool, one that may be decisive in the creation of trust and the prevention of the experience of loss of control. Early information and advice on self-coping strategies that work are also central to create security and trust that professionals may use to build a relationship. Thus, it is important that the local and specialist health services, as well as schools and workplaces, focus on a further elevation of practical/theoretical competence in the grief and trauma field. In addition, it will be important to increase the focus on inter-municipal crisis teams in order to give professionals sufficient experience in this special field.

Increased chemistry in the encounter. Meeting people struck by grief and trauma may be challenging, both for professionals and others (Dyregrov, K. & Dyregrov, A., 2008). People who have had their worlds suddenly turned upside down are extremely vulnerable to how others address them. Both in this study and in previous studies this is exactly what the bereaved point to when they ask for more understanding, empathy and chemistry with their helpers. That the «chemistry» between the two parties is «right» is also decisive when applying good professional competence in the meeting with the bereaved. One of the leading researchers on psychotherapy in the world, Bruce Wampold, is concerned with the components that make psychotherapy effective. He holds that if you ask the patients what is important to them, the answer is the relationship with the therapist. They want therapists who inspire confidence, who understand them, and who work for their interests (Wampold & Budge, 2012). The key to a «good chemistry» thus lies in open, good and secure interaction and communication processes between the bereaved and the helper. A fundamental condition for this is «suitability» in the

helper, that is, this person must be able to cope with and endure in extreme situations and keep calm and secure, so that the bereaved will be able to trust the helper's competence and ability to help. Further, the helper must be able to create a good relationship by «seeing» and listening to the individual, choose helpful measures for individuals and families, and give help so that it is regarded as helpful (Dyregrov, K. & Dyregrov, A., 2008). Here, it is crucial that the helper appears as a professional, and that there is an interaction with the person struck by crisis in which feedback from the affected person influences the practice of the helper, for example, by more systematic use of feedback systems.

When young siblings lack greater empathy and adaptation based on a genuine understanding of what they have experienced, these are important signals to the school. Such signals are consistent with results from previous studies on bereaved young people and the school system (Cohen & Mannarino, 2011; Dyregrov, K., 2009), and these indications are very important when one considers the serious educational consequences that a traumatic loss may have for young people (Dyregrov, A., 2004). As documented in the Norwegian context, teachers are concerned that they do not have sufficient knowledge about the topic, and find that they often fall short when meeting bereaved students (Dyregrov, A., Dyregrov, K., & Idsøe, 2013). They point to the need for action plans and written procedures, more knowledge about grieving among teachers, clarification of roles and action chains in the school system, advice on how the scope of action in the Education Act may be utilized for grieving students, and ideas for concrete individual adaptation measures (Dyregrov, K., Endsjø, Idsøe, & Dyregrov, 2014; Hart & Garza, 2012–2013). Still, the teachers also point out that they cannot take the role of «hobby psychologist» to grieving students, and that the demarcation can be difficult, but must be clarified nonetheless (Dyregrov, A. et al., 2013).

The advice of the bereaved for the helpers.
More than 80 bereaved parents and siblings gave the following pieces of advice to the helpers about what is important in the follow-up of the bereaved after traumatic losses:

- Take contact – offer help.
- Repeat the contact if one refuses at first.
- Give us a contact person that can ensure continuity in the support services.
- Include the bereaved, both those with psychological and biological closeness to the deceased, in the follow-up.
- Base the help on competence and communicate it with empathy.
- Be flexible, listen to what we need, but take charge when it is needed.
- Give us clear information at an early stage about how the death happened, normal grief and crisis reactions, what will happen next, where and from whom we may receive help. Repeat the information.
- Help us get in contact with a psychologist and other necessary groups of professionals.

- Help us get in contact with others who have experienced the same.
- Offer adaptation at school and work, without us having to ask for it.

To summarize, one can see that the advice involves all the central elements in the proactive model for follow-up that the public authorities instructed to be deployed after the terror on 22nd July 2011, and which those bereaved after violent and unnatural deaths have previously asked for, not only in Norway (Dyregrov, K., 2002; Dyregrov, K. & Dyregrov, A., 2008; Dyregrov, K. et al., 2000; Dyregrov, K. et al., 2014a; Henriksen, 2002; Hjemdal, 2007; Reme et al., 2003), but also internationally (McMenamy et al., 2008; Wilson & Clark, 2005). The survivors of the 2011 terror attack also asked for follow-up on the same principles (Dyb, Jensen, Glad, Nygaard, & Thoresen, 2014).

Strengths and limitations of this study.
The present study is part of a series of user surveys that explore the experiences of the bereaved with the support systems after traumatic deaths, but is the first to examine the support services given to the bereaved after the terror of 22nd July 2011. We regard it as a strength that this is studied by a broad group of researchers with long experience from the field (theory/research triangulation). Although, from a user perspective, it is a strength that the data are obtained through self-reporting, it is a weakness that we have not been able to obtain comparable public records on the same topic. Another weakness is that the article is based on cross-sectional data, which implies that one cannot draw firm, causal conclusions. A relatively small sample size, but one that still represents a relatively large proportion of affected families, means that while the generalizability of the quantitative data for this special population is regarded as good, there will be some limitations in statistical generalization to all traumatized bereaved. In addition, one would like to have baseline data from earlier than one-and-a-half years after the event, which was not possible due to financial challenges. The opportunities for theoretical/analytic generalization (transferability) from the rich qualitative data are considered good.

Conclusion

When those bereaved by a traumatic death provide such similar advice to the support systems repeatedly through many years and in many different studies, we need to listen to them. The proactive model for follow-up seems to have raised the user satisfaction with the help received. At the same time, the contents of this help can be improved by raising the helpers' competence, improving the «chemistry», and increasing the duration of follow-up. Better routines and systems will partially remedy deficiencies, but an increased understanding among the helpers of the situation of the bereaved is also necessary. Last but not least, the advice from the bereaved needs to be listened to so that the advice can be adapted to the situation of the individual and the family. Then the «users» are taken seriously, and their «empowerment» and autonomy are strengthened.

1. A hotel where the relatives waited for messages about who had survived and who had died. [↩]

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Abstract

The psycho-social follow-up after the terror of July 22nd 2011 as experienced by the bereaved

During the terror attack of 22nd July 2011, at Utøya, 69 mainly young people were killed, leaving more than 210 siblings and parents behind. In the immediate aftermath of the attack, the Norwegian Government initiated a proactive psychosocial follow-up for bereaved families, implying that the service system should initiate contact with those who had lost a family member. In a combined

quantitative and qualitative study a year and a half after the terror attack, we describe the proactive model for psychosocial support and report on how bereaved parents (*n* = 67) and siblings (*n* = 36) evaluate different aspects of the model. In line with previous studies, bereaved parents and siblings applauded the proactive model for follow-up, but called for more empathic, stable and educated helpers.

Keywords: traumatic bereaved, proactive follow-up, terror, user perspective.

Author affiliations: Kari Dyregrov – Center for Crisis Psychology, Bergen, Norway and Bergen University College, Bergen, Norway; Pål Kristensen – Center for Crisis Psychology, Bergen, Norway and Telemark Hospital, Norway; Iren Johnsen and Atle Dyregrov – Center for Crisis Psychology, Bergen, Norway.

Contact information: Kari Dyregrov, Center for Crisis Psychology, Fortunen 7, N-5013 Bergen, Norway. Email: kari@krisepsyk.no.

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This is a peer-reviewed paper.

Kari Dyregrov

Kari Dyregrov er sosiolog og forskningsleder ved Senter for Krisepsykologi i Bergen. Hun tok sin doktorgrad på foreldre som mister barn ved traumatisk død, og deres reaksjoner, behov og tilbud om hjelp. Hun har en rekke publikasjoner på feltet.

Pål Kristensen

Pål Kristensen er forsker og psykologspesialist med fordypning i klinisk barne- og ungdomspsykologi. Han tok doktorgrad på sorg etter tsunamikatastrofen i 2004 og rasulykken i Vassdalen i 1986.

Iren Johnsen

Iren Johnsen er sosiolog og doktorgradskandidat ved Senter for Krisepsykologi i Bergen. Hun har også bidratt til utviklingen av nettsiden sorggrupper.no.

Atle Dyregrov

Atle Dyregrov er spesialist i klinisk psykologi og en av grunnleggerne av Senter for

Krisepsykologi i Bergen, hvor han har vært daglig leder i 25 år og nå er faglig leder. Han har utgitt en rekke bøker, blant annet *Hvordan lede sorggrupper*.