

OMEGA, Vol. 68(4) 347-366, 2013-2014

PEER SUPPORTERS' EXPERIENCES OF A BEREAVEMENT FOLLOW-UP INTERVENTION FOR GRIEVING PARENTS*

ANNA LIISA AHO, PHD

PÄIVI ÅSTEDT-KURKI, PHD

MARJA KAUNONEN, PHD

University of Tampere, Finland

ABSTRACT

The aim of this study was to describe the experiences of peer supporters of a bereavement intervention for grieving parents and how the program should be developed further. The intervention included: a support package for grieving parents, peer supporters' contact, and healthcare personnel's contact with parents. The sample included 16 peer supporters. Data were collected via open-format questionnaires and telephone interviews and analyzed by content analysis. Peer supporters perceived the intervention and its viability as mostly good. Parents' willingness to receive support and peer supporters' good resources were important for the follow-up contact. However, the peer supporters' resources were insufficient to meet parents' unexpected needs. Continuous training and systematic supervision of peer supporters is needed. Study results suggest that support interventions aimed at grieving families

*The Finnish Nurses Foundation, the Finnish Association of Nursing Research (HTTS), the Finnish Cultural Foundation, the Finnish Nurses Association, Finnish Concordia Fund and competitive research funding from the Pirkanmaa Hospital District have provided financial support for the study.

need a greater number of male supporters, as fathers hope to receive more support from their male counterparts. Inter-organizational cooperation in supporting parents is important and must be further developed.

INTRODUCTION

The grieving process after the death of a child is long-lasting and burdensome for many parents (Arnold & Gemma, 2008; Wing, Burge-Callaway, Clance, & Armistead 2001). The process includes strong feelings and reactions and also changes in parents' identity, life, future perspectives, and social environment. The change leads to rebuilding new purposes and meanings (Barrera, O'Connor, Mammone, Agostino, Spencer, Nicholas, et al., 2009; Bellali & Papadatou, 2006; Davies, 2004; Dyregrov & Dyregrov, 2008; Kavanaugh & Hershberger, 2005). The death of a child causes a number of negative outcomes to parents' health and well-being. The loss may lead to parental morbidity and mortality. In addition, it may increase the number of physician visits and the need for psychiatric hospitalization and outpatient care, which may in some cases lead to unemployment. (Gudmundsdottir, 2009; Li, Hansen, Mortensen, & Olsen, 2002; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003; Qin & Mortensen, 2003). Grief can become pathological (Prigerson, Vanderwerker, & Maciejewski, 2008) or lead to a posttraumatic stress reaction (Badenhorst, Riches, Turton, & Hughes, 2006; Turton, Badenhorst, Hughes, Ward, Riches, & White, 2006) and especially the life of grieving fathers may lose meaning and they may feel that they are wasting their lives (Kitson, 2002; Samuelsson, Rådestad, & Segesten, 2001).

Because of the negative outcomes after the death of a child, it is important to provide more support to grieving parents to prevent these negative outcomes. Appropriate social support, for example the ability to speak openly and honestly about feelings, has a positive impact on the grieving process of parents (Arnold & Gemma, 2008; Hogan & Schmitt, 2002; Kreicbergs, Lannen, Onelov, & Wolfe, 2007; Murphy, Johnson, Cain, Das Gupta, Dimond, & Lohan, 1998; White, Walker, & Richards, 2008), thus social support is a central way to help parents.

Parents report that the spouse and other significant people in their lives are the main sources of social support (Benkel, Wijk, & Molander, 2009). However, expectations for support and perceived support do not always match and problems exist in the parental relationship or the social network (Badenhorst et al., 2006; Cacciatore, DeFrain, Jones, & Jones, 2008; Dyregrov & Dyregrov, 2008; Kavanaugh, Trier, & Korzer, 2004; McCreight, 2004). Significant others sometimes fail to understand parents' long-lasting grief, as well as do other grieving parents (DiMarco, Menke, & McNamara, 2001; Reilly-Smorawski, Armstrong, & Catlin, 2002; Webel, Okonsky, Trompeta, & Holzemer, 2010).

Parents have reported positive experiences of peer support as they have been able to talk openly and express their feeling and also laugh without being misunderstood. The relationship with peers decreases parents' loneliness. Participation in a peer support group provides parents a time and place to grieve (Geron, Ginzburg, & Solomon, 2003; Murphy, 2000; Reilly-Smorawski et al., 2002). It has helped to maintain attachment to the deceased child (McCreight, 2004), to deal with spiritual issues (Geron et al., 2003; Reilly-Smorawski et al., 2002), and increased open communication between parents (McCreight, 2004; Murphy, 2000; Reilly-Smorawski et al., 2002). In addition, parents have been able to share different types of knowledge and practical issues with peers, such as information about grief and coping strategies or funeral arrangements (DiMarco et al., 2001; Dyregrov & Dyregrov, 2008; Geron et al., 2003; Reilly-Smorawski et al., 2002).

Internationally, only some supportive interventions have been implemented among grieving parents after the death of a child (Chambers & Chan, 2004; Rowa-Dewar, 2002). The interventions have been varied and consisted of a group support session, personal contact with a skilled grief worker or hospital chaplain for bereaved parents (DiMarco et al., 2001; Murphy et al., 1998; Murray, Terry, Vance, Battistutta, & Conolly, 2000; Oliver, Sturtevant, Scheetz, & Fallat, 2001; Reilly-Smorawski et al., 2002). The aims of the interventions were to offer information, skill-building, and emotion focused support for parents or the whole family and their social network.

Even though grieving parents' experiences of peer support are positive and peer support is also acknowledged at the organizational level, systematic collaboration is scarce and research evidence about collaboration between healthcare and peer support organizations is lacking in Finland (Ministry of Social Affairs and Health, 2009). In addition, the mortality rate of children in Finland is very low (e.g., about 200 stillbirths and 200 perinatal deaths yearly; Tilastokeskus, 2012.) Also, in Finnish culture it is not typical to express one's feelings in public (Aho, 2010).

There is little research evidence especially regarding the viewpoint of peer supporters' experience of providing support for other grieving parents. In this study, a bereavement follow-up intervention was developed in which support for grieving parents was implemented in collaboration between healthcare professionals and peer supporters. This has been a novel perspective to develop the program. The aim of the intervention was to improve the provision of aid, affect, and affirmation for grieving parents after leaving the hospital (see more details in Methods). In this study, the effect of the support intervention was studied from the parents' perspective (Aho, Tarkka, Åstedt-Kurki, Sorvari, & Kaunonen, 2011; Nikkola, Kaunonen, & Aho, 2013; Raitio, Kaunonen, & Aho, submitted for review); however, when evaluating the effectiveness of interventions, it is important to assess their feasibility, acceptability, and practicality (Blackwood, 2006). Thus we also need knowledge from the perspective of the implementers (Aho, Åstedt-Kurki, Tarkka, & Kaunonen, 2011).

THE PURPOSE AND RESEARCH TASKS

The purpose of this study was to describe the experiences of peer supporters of a bereavement follow-up intervention for grieving parents and how it should be developed further. The research tasks were to:

1. describe peer supporters' experiences of intervention implementation;
2. describe peer supporters' experiences of the content of parental support; and
3. describe how peer supporters would develop the bereavement follow-up intervention further.

METHODS

Design

This study is part of a larger action research study project in which a bereavement follow-up intervention was developed and evaluated. A qualitative approach was adopted for the study as the aim was to elicit supporters' experiences of the implementation of the intervention and suggestions for further developing it and bereavement follow-up care. Using the action research cycle, the bereavement follow-up intervention was developed by the authors mainly on the basis of theoretical knowledge and a synthesis of clinical and scientific knowledge (see details in Aho, Åstedt-Kurki, et al., 2011).

The peer supporters received training on intervention implementation before starting the study. Peer supporters needed to have personally experienced the death of their child, as well as they needed to participate in a peer support training.

The support intervention is called a follow-up program, starting after the discharge from hospital and continuing according to parents' needs. The unique components of the follow-up intervention after discharge from hospital included:

1. a support package;
2. peer supporters' contact with parents; and
3. healthcare personnel's contact with parents.

The Finnish support package included informational letters (e.g., information on causes of child death (neonatal and perinatal deaths), information on the mourning process, parents' grief, children's and adolescents' grief, grandparents' grief, effect of the death of a child on family members and their coping), as well as poems and stories about the loss of a child. All parents received this information in written form. Peer supporters' initial contact with parents occurred via telephone about a week following the death of the child, and at a later date mutually agreed by those involved in the form of a home visit. All parents were contacted by a peer supporter within one week following the death. The healthcare personnel's telephone contact after leaving the hospital (2-6 weeks following the death) was made by the primary nurse, who had been present at the time of the child's death in

hospital. The aim of the bereavement follow-up intervention was to provide affirmation, affect or emotional support, and concrete aid support for grieving parents collaboratively by peer supporters and healthcare professionals.

Participants

Peer supporters ($n = 16$), who had participated in the intervention, volunteered for the study. The intervention was implemented in the hospital units where a child could die (intensive care unit, maternity ward, emergency room) at the age of 3 years or younger (including perinatal deaths in the 22nd week of gestation or fetuses weighing over 500 grams). The majority of the peer supporters were women with a mean age of 42 years (see Table 1). Most peer supporters were married (88%) and the majority had 1-3 children. The majority had completed high school (88%), while 44% had attained an academic degree or post-secondary qualifications (38%). The time that had passed since the death of the child ranged from 3 years to 23 years, with a mean of 11 years. The subjects had served as peer supporters on average 6 years and most (69%) had also served as a group facilitator in grief groups, on average 1.5 years. They had implemented the intervention

Table 1. Background Information on Intervention Participants

Variable	<i>n</i>	%
Gender		
Female	14	88
Male	2	12
Age		
25-44	11	69
45-55	5	31
Marital status		88
married	14	12
divorced	2	
Number of children		6
no children	1	75
1-3	12	19
4-6	2	
Education		13
upper comprehensive school or comprehensive school	2	87
high school	14	
Professional qualifications		12
lower level diploma or upper secondary level vocational qualifications	2	38
post-secondary qualifications	6	6
polytechnic degree	1	44
academic degree	7	
Years in peer support work		75
1-10	12	25
11-30	4	

one to nine times, on average three times. Of the peer supporters, 67% reported that the intervention had increased the amount of their voluntary work.

Data Collection

Data were collected via an open-format postal questionnaire and a telephone interview conducted by Anna Liisa Aho. The postal questionnaire included three open-ended questions to determine the positive and negative experiences of the intervention among peer supporters and their suggestions for further developing the bereavement follow-up intervention for grieving parents. In addition, the questionnaire included demographic data for the participants.

Informed consent for the telephone interview was given by participants in the questionnaire. Audio recording of the interviews was done with permission of the participants. The themes of the telephone interviews were based on peer supporters' responses to the questionnaire. The aim was to provide insight into and clarify vague answers. Interviews lasted from 30 minutes to 45 minutes.

Data Analysis

The data were analyzed using inductive qualitative content analysis (Graneheim & Lundman, 2004). First, the materials from the open-ended questions were read through while recording specific observations about the text which required clarification in the interview. Second, the interview data were transcribed verbatim. The analysis continued by combining the data, by reading the material and by condensing it in accordance with the research tasks. The codes + and – were used in the condensation process to describe issues that were considered positive and negative (see Figure 1).

The condensed themes were grouped by combining similar themes under a descriptive concept. Further, the grouped themes were divided into sub-categories by similarities and dissimilarities, which were then given a descriptive label. The analysis was continued by grouping the sub-categories and by labeling the higher order categories in accordance with the intervention components. Data analysis was carried out by using the Atlas.ti software (<http://www.atlasti.com/>).

Ethical Considerations and Rigor

Ethical Principles of the Declaration of Helsinki were followed. Permission to conduct the research was obtained from the board of the support organization. Informed consent was obtained from the study participants. The data consisted of questionnaires and audio tapes, which were kept in a locked place and will be destroyed accordingly.

The researcher (Anna Liisa Aho) had met the study participants in conjunction with intervention training. This sub-study of action research enabled discussion between the intervention participants and the researcher about the success of the

Original utterance	Condensed utterance	Grouped utterance	Subcategory
"We're there with them" (+)	Being with parents	Presence	Emotional support
"We discuss things like the child's funeral, the grief of parents, mother and father, differences between their grief, how children and grandparents grieve, how family and friends have taken it, whether they still have all their friends left and how they coped with getting back to work . . ." (+)	* Discussions about the child's funeral, grief of mothers and fathers, differences between the grief experienced by parents, children's grief, grief of grandparents, attitudes of family and friends, keeping friends, returning to work and experiences of this	Discussions	
"Parents have the need to talk and they are willing to tell about their situation . . ." (+)	Listening to parents	Listening	
"I try to determine what the situation is like in the family . . ." (+)	Determining family situation	Identifying coping responses	
"If there seems to be abnormal grieving . . ." (+)	Identifying pathological grief	Identifying sources of social support	
" . . . we make sure they've got the support . . ." (+)	Ensuring support		
"whether they've been left alone with their grief or need help . . ." (+)	Identifying the need for support		

Figure 1. Example of data analysis.

implementation and the assessment of the feasibility of the intervention. Those participating in the intervention openly reflected upon both their negative and positive experiences of the intervention. The data for the study were collected only from peer supporters who implemented the intervention. Because of the qualitative approach the results cannot be generalized. The data were re-analyzed by using the Atlas.ti software which improved the reliability of the analysis.

FINDINGS

Peer Supporters' Experiences of the Intervention Implementation

The experiences of peer supporters of the intervention implementation are described in Figure 2. The results follow the components of the intervention, which formed the categories.

Grouped theme	Subcategory	Category
Distributing the support package Appropriate timing Support package not given	Viability of the support package	Support package
Versatile content Limited content	Comprehensibility of the support package	
Varied types of contact Suitable timing of contact Individual number of contacts Family as the recipient of support	Feasibility of follow-up support	
Being helped Receiving further support Uncertainty of survival Parents' negative feelings	Parents' capacity to receive support	Follow-up contact
Personal experiences Personal resources Joy of helping Negative feelings	Supporters' resources	
Adequate training Supervision Organizational resources	Organizational preconditions	Cooperation among supporters
Shared goal Trust	Viability of cooperation	
Efficient information to parents Timely recruitment Adequate information transfer	Viability of information transfer	

Figure 2. Experiences of the intervention among peer supporters.

Bereavement Support Package

Viability of the Support Package

The fact that the support package was distributed to parents as part of the intervention was considered important by the peers. The time of distributing the package, before leaving the hospital, was deemed appropriate. Peer supporters noted with regret that some parents had not received the package.

Comprehensiveness of the Support Package

The information included in the support package was deemed very diverse but inadequate in terms of content as it was limited to infant mortality and offered only in Finnish, which made it impossible to distribute it to parents who could not speak Finnish and who had lost an older child.

Follow-up Contact Provided by Peer Supporters

Feasibility of the Follow-up Contact

The *types of contact* between peer supporters and parents turned out to be varied. Telephone calls and meetings were the primary forms used, but text messages and e-mails were also used. The advantages of making the telephone call were the freedom to determine the time for the meeting according to the schedules of peer supporters and parents and the chance for parents to be interviewed in their home environment. However, especially the poor availability of the parents, difficulty of finding a convenient time for discussion, and of communicating via telephone with both parents were perceived as negative aspects. Peer supporters believed that the telephone call was a good way to make initial contact, but if it was the only form of contact, if there were several calls or the call tended to drag on for a long time, the telephone call was perceived as a negative thing.

On the phone you have to think more carefully, until you know them, about what they think and how they feel.

Peer supporters mainly visited parents in their homes, but also met them through various events and peer support groups. For peer supporters, a positive aspect of the home visit was particularly the chance to meet the family's children. Peer supporters may have regarded the home as too intimate a place, and some parents had also expressed reservations about the purpose of the home visit.

It's easier to meet, you can offer comfort by giving a hug or encourage them by placing your hand on the bereaved person's upper arm, and by looking into their eyes and facing their grief "live."

Peer supporters believed that the timing of the follow-up contact, 7 days after the child's death, was an appropriate time to initiate the support intervention. If

parents received initial support elsewhere or if peer supporters themselves felt apprehensive about meeting parents in the acute stage of grief, the timing was perceived as too early. After the initial support, the contacts between peer supporters and parents continued according to parental needs. Some parents preferred to be contacted only after the child's funeral.

The family was really grateful that I was able to come to their home so quickly.

It would be advisable to make that first contact without delay because their distress is so great, and in a way everything you can help them with is right there.

Peer supporters reported that the *individual number of contacts* prescribed in the intervention depended on the needs of parents while, in practice, the supportive relationship lasted longer. A short supportive contact was possible to implement through peer support resources to convey parents information about the availability of support.

... this model, the follow-up phone call, home visit and referral to a group, I think it's very short. It has not worked in any of the cases.

My experience tells me that these supportive relationships last much longer and the parents wish they could have a longer relationship, and that's what we do if that's what they want.

The intervention was aimed at supporting the whole *family*, which was deemed important by the peer supporters. They also supported the family's children by discussing and playing with them. Peer supporters felt that support for fathers was important, but difficult to implement in practice because mothers tended to take up more than their fair share of space or blocked the attempts to make contact with the father. Some fathers were also surprised to meet a female peer supporter.

It's good to discuss with both parents at the same time because you can make them think about things from the perspective of both parents.

Parents' Capacity to Receive Support

Peer supporters believed that the most important aspect contributing to the success of the follow-up contact was that parents were receptive to support. This involved being helped and receiving further support. Being helped as a bereaved parent was shown, among other things, in parents' willingness to discuss and openness and easy communication with supporters. It also involved parents' gratitude for and satisfaction with and positive feedback on the support.

They wanted to talk and I spent two hours with them, they were really open and there was a warm atmosphere, they thanked me genuinely and hugged me when I left. I interrupted the meeting because they were so tired.

Peer supporters did not always believe in parental survival, as some parents had difficulty accepting support and had negative feelings. Parents were unwilling to

discuss with peer supporters, the atmosphere was uncomfortable, or parents did not respond to the supporter's attempts to contact them. Parents could deem the support unnecessary if they received support elsewhere. Peer supporters perceived as positive the further support received by parents, such as crisis aid, a psychiatrist's consultation, or referral to a peer support group, which was arranged when necessary. Parents' negative feelings included in particular the nervousness and aggressiveness of the fathers, parents' supernatural experiences, and mental health problems. The supporters found those feelings frightening and baffling. Peer supporters reported that parental discord, such as an ongoing separation, adversely affected the supportive relationship or cut it short.

Peer Supporters' Resources

Peer supporters believed that their strengths and resources lie in their personal experience of losing a child and peer support work either as an individual peer supporter or a group facilitator. However, the long time that had passed since the death of their own child reduced their capacity for empathy.

The personal resources of the peer supporters included open-mindedness, high tolerance for uncertainty, a courageous, positive mindset and the ability to commit themselves to the supportive relationship. Good communication skills, the ability to understand different kinds of families and desire to support the coping of parents were an important part of their resources. Peer supporters also emphasized their own balanced family relationships as their own personal resources.

I think of myself as a tool. Basically it's my own background and the belief that you can survive this on your own and with the help of others. Life can go on, even though your child is dead.

... but you really need to commit yourself to the relationship because you can't leave these families and you just have to have the time and contact them if you say you will.

Peer supporters believed that their resources were depleted, for example, because of stressful family circumstances.

It's been difficult to find a peaceful atmosphere and space to make the phone call, I was afraid that my own living child would wake up in the middle of the afternoon nap and start to cry, or that my family would come and "disturb" a situation that is extremely delicate.

Peer supporters experienced the joy of helping when supporting grieving parents and both groups perceived this as an important and rewarding activity. The follow-up contact also aroused negative feelings such as anxiety, tension, fear, and uncertainty. The fear mainly focused on initiating the discussion and on one's inability to carry on a conversation, fear of rejection, and the reactions of parents. Supporting grieving parents was regarded as a stressful and difficult task, after which the supporters felt mentally and physically drained. The contact also

reminded them of their personal experiences concerning the treatment or death of their own child.

Before the first phone call I felt frightened, nervous and apprehensive about how I can respond to another person's grief.

Your own grief is bound to surface more strongly during and after the support meeting.

Organizational Preconditions

Peer supporters believed that the peer supporter and group facilitator training related to the intervention was a good basis and adequate for peer support activities.

Peer support training is and was useful; we examined issues like what is your capacity to listen and be receptive and consider these things. Those are important issues. I would have not known what to do without the training.

However, they wished to receive more training, especially on how to support fathers. Supervision was provided at the events organized by the peer support association and in personal discussions with leaders of the association, which promoted the well-being of supporters. Organizational resources included feedback given by the association, whereas the feedback from families on their coping was considered insignificant. Peer supporters also wished they could work in pairs, as this would provide them with a sense of safety and support when meeting the family. The organization covered the travel expenses, but otherwise the work was on a voluntary basis. Peer supporters felt uncertain about their role in the supportive relationship as to whether they were parents who had lost a child or representatives of the peer support association.

Cooperation Between Supporters

Viability of Cooperation

Peer supporters perceived their cooperation with healthcare professionals as very viable. They had a mutual goal, supporting parents, and mutual trust.

Cooperation is important, it enhances the dialogue between healthcare and peer supporters, that is, what we could do together.

Viability of Information Transfer

Information transfer between different organizations was mostly perceived as efficient. Peer supporters believed that healthcare staff had done a good job informing parents about peer support, provided information about support services at the right time, and transmitted a sufficient amount of background information on the parents to the peer support association. At times the information was considered

insufficient and consent for the peer supporter's contact was requested too early. Peer supporters also complained about the scarcity of background information on parents and slow information transfer. Detailed background data on parents helped the peer support association to find a peer supporter who lived close to the parents or had experienced a similar loss and to adapt to the family's circumstances before the supportive relationship began. If there was a delay in transferring the information, there was a delay in providing the family with support.

Sometimes their background details were quite hard to get. The nurses would leave nothing but the mother's phone number.

Peer Supporters' Experiences of the Content of Parental Support

Peer supporters provided grieving parents with emotional, concrete, and informational support (see Figure 3). Emotional support included presence, discussions, listening, helping to express feelings, creating hope, identifying coping reactions, identifying sources of social support, being available, search for meaning, identifying and meeting needs, serving as a role model on survival, and agreeing to meet again.

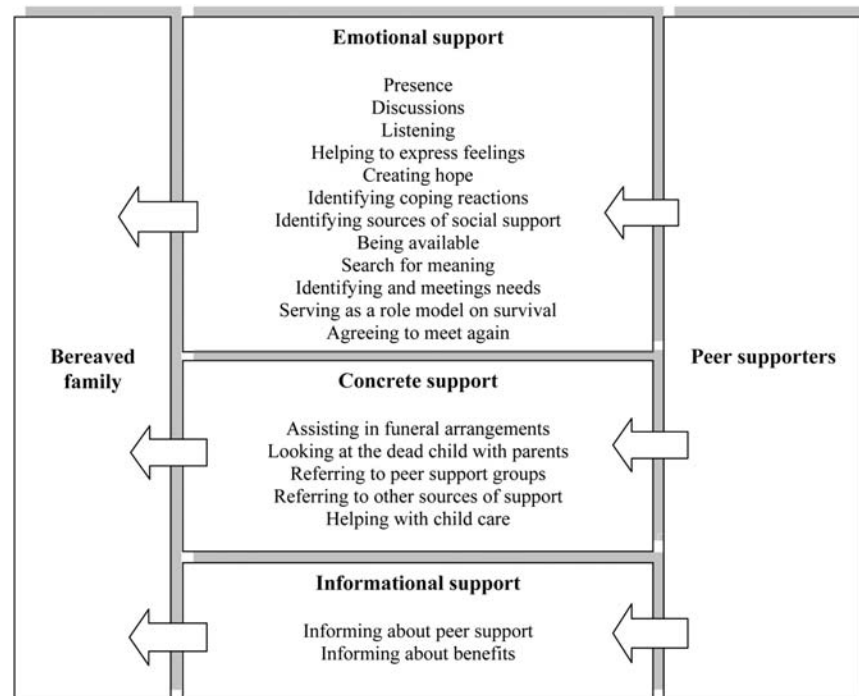


Figure 3. Parental support provided by peer supporters.

responses, and sources of social support. In addition, emotional support included being available, searching for meaning, identifying and meeting the needs of parents, serving as a role model for survival, and agreeing to meet them again. The discussions focused on the grief and coping of other family members, the funeral arrangements and the actual funeral, everyday matters, and perceptions of the support received from family and friends or peer supporters. Discussions also included family planning and the support given by healthcare personnel. Peer supporters also sought to answer questions posed by the family's children. A key aspect of the support provided by peer supporters was sharing their experiences of the death of their own child.

Concrete support included assisting in funeral arrangements, looking at the dead child with parents, referring to peer support groups and other sources of support, and helping with child care. Informational support included informing about peer support and benefits after the death of a child.

It was important to try to tell them honestly about my own recovery and how life will move forward, although the grief never goes away.

Suggestions for Developing the Intervention

Peer supporters made suggestions for improving the intervention (see Figure 4). They suggested that new content should be added to the support package, particularly information on the schedules of peer support groups, on the death of an older child, and on other sources of help. Peer supporters believed that the support package should also include information about the contact provided by peer supporters because parents could forget it.

Peer supporters expressed a wish that the follow-up contact should include a written foreword to the telephone contact and that the number and type of contacts should be tailored to meet the needs of families. In their opinion, more organizational resources should be allocated to the follow-up contact, and especially there should be more training about the grief of fathers, more supervision, and more male peer supporters. Feedback on family coping from the association and on the initial contact with the family should be obtained.

As for the cooperation among peer supporters and healthcare personnel, it was suggested that support be offered more systematically to grieving parents and that multilingual support be made available. In addition, peer supporters wished to improve information transfer, especially concerning more comprehensive background data on parents from healthcare personnel.

DISCUSSION

The purpose of the study was to describe the experiences of peer supporters of a bereavement follow-up intervention for grieving parents and how it should be

Support package	Follow-up contact	Cooperation among supporters
Content * Schedules of peer support groups * Information on the death of an older child * Information on other sources of help * Information on the contact provided by peer supporters	Feasibility of intervention * Written foreword to the phone contact * Number/type of contact according to family needs Organizational resources * More training on the grief of fathers * More clinical supervision * Engaging more male peer supporters * More work in pairs * Obtaining feedback on family coping from the association * Initial contact/follow-up contact with family from the association	Practice * More systematic provision of support for parents * Offering multilingual support for parents Information transfer * Providing more comprehensive background data on parents for peer supporters

Figure 4. Peer supporters' suggestions for developing the intervention.

developed further. The unique components of the intervention after discharge from hospital included a support package, peer supporters' contact, and healthcare personnel's contact with parents. Peer supporters believed that the information given to parents in the support package was an important component of the intervention, because it included a wide range of information needed by parents (e.g., Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Dyregrov & Dyregrov, 2008) and also because it made available peer experiences, such as using poems and references to literature. According to the peers, the support package should be developed to provide more information for parents whose child had died at other ages or from other reasons. The package should also include contact details for other sources of support and further information about the peer supporter's contact, just to remind parents of the possibility of support.

The main positive experiences of peer supporters of the follow-up contact were its feasibility, parents' capacity to receive support, peer supporters' resources, and organizational preconditions. The support intervention took many forms, but mostly it was implemented by telephone calls or home visits. Peer supporters were apprehensive about the home visits and believed that some parents also perceived it as misplaced. This result may indicate the cultural traditions in Finland, where a family's home is a very private place. In spite of previous results (Aho et al., 2011; Nikkola, Kaunonen, & Aho, 2013), home visits were perceived positively, because the peers were able to understand the family situation as a whole and offer support to the whole family. In the future, parents' opinions about the meeting place should be consulted more thoroughly.

The contact between peers and parents took place more frequently and lasted longer than it was planned in the study, as peer supporters continued the contact according to parents' needs. This led to problems in terms of peer supporter resources, since in the beginning it was difficult for them to predict the commitment required. Short-term support was feasible through peer support resources, but if necessary, long-term individual support for parents would have been possible. The peer supporters were continuously available. In addition, 97% of mothers and 99% of fathers endorsed continuation of the intervention (Aho et al., 2011; Nikkola et al., 2013).

One of the aims of the intervention was to increase support for fathers who had lost a child, which was deemed important by peer supporters but a challenging task to implement. It appears that family-focused care in supporting grieving parents is not realized equally for both parents. Previous studies (Aho, Tarkka, Åstedt-Kurki, & Kaunonen, 2009; Kitson, 2002; Samuelsson et al., 2001) have also shown that fathers feel that they have been left without support. Development suggestions made by peer supporters highlighted the need for male support persons, which was also what fathers wished for. It would thus also be important to engage fathers in peer support work. The effectiveness of the intervention on the grief and coping of fathers indicates that the support intervention increased fathers' personal growth and helped them cope (Aho, Tarkka, et al., 2011).

One of the most crucial aspects of the follow-up contact was the willingness of parents to receive support, which was mostly good. Nevertheless, that some parents were not willing to discuss with peer supporters their negative feelings, such as a father's aggressive behavior, disconcerted the peers. It is important that peers see expression of feelings as a natural part of grief and encourage grieving persons to do so even if they are not professional helpers. It would also be important to repeat the offer of support to parents who have refused it as the mood and need for support among grieving persons may vary from one moment to another (e.g., Aho et al., 2009; Dyregrov, 2004; Dyregrov & Dyregrov, 2008).

Expenses caused by the intervention to the peer supporters were covered by research funds, but the peer support activities were based on voluntary work. It would be important to extend the intervention to cover those healthcare organizations that encounter grieving parents. This would necessitate more active peer supporters and cooperation with other third-sector organizations in supporting parents and organizing peer support training which peer supporters are required to attend. An additional requirement is the positive attitude of the managers of healthcare organizations towards supporting parents and the importance of cooperation with the third sector.

While cooperation between health professionals and peer supporters had previously been limited, the intervention increased cooperation between them in supporting grieving parents. Cooperation was perceived as important. The child's named nurse contacted the peer supporters only after receiving permission from parents for the intervention. The professionals encouraged parents to contact the peers, and vice versa. Peer support enabled sustained and intensive support for grieving parents, which would have been impossible to organize using solely professional resources. Healthcare personnel were relieved that families receive immediate support from peer supporters (Aho, Tarkka, et al., 2011). Suggestions were even made that the responsibility for the follow-up contact should be completely devolved to peer supporters. Previous study results show (e.g., Dyregrov, 2004), however, that parents need different types of support from different types of support persons. Peer supporters are not capable of answering questions about the child's illness and cause of death. One of the suggestions for developing cooperation concerned a more detailed description of the preliminary data on parents. This requires parental consent because health professionals are bound by confidentiality when transmitting information.

The purpose of the intervention was to increase emotional, informational, and concrete support for parents after the death of a child. Peer supporters reported that the support given to parents did indeed comprise these forms of support. Peer supporters drew on their own experiences, and as role models for survival provided support for the whole family, including the children. Parents received support tailored to their needs (DiMarco et al., 2001; Reilly-Smorawski et al., 2002; Webel et al., 2010). Compared with support provided by health professionals, peer support specifically focused on searching for meaning, identifying and meeting the parents'

needs and serving as a role model for survival, and helping with practical matters such as child care. (Aho, Tarkka, et al., 2011).

Systematic collaboration between healthcare professionals and peer support organizations is a relatively recent idea. This intervention enabled acute grief support, continuous support, and gave grieving parents the chance to contact their peers. These study results describe the intervention and experiences of it, which could be applied when developing and fostering collaboration. The results support the need for peer supporter training and clinical supervision.

ACKNOWLEDGMENT

We wish to thank the peer supporter who participated in the intervention and in the study.

REFERENCES

- Aho, A. L. (2010). Isän suru lapsen kuoleman jälkeen. Tuki-interventio ja sen arviointi. Acta Universitatis Tamperensis 1551. Tampere University Press. Tampere.
- Aho, A. L., Åstedt-Kurki, P., Tarkka, M.-T., & Kaunonen, M. (2011). Development and Implementation of a bereavement follow-up intervention for grieving fathers: An action research. *Journal of Clinical Nursing*, 20, 408-419.
- Aho, A. L., Tarkka, M.-T., Åstedt-Kurki, P. & Kaunonen, M. (2009). Fathers' experience of social support after the death of a child. *American Journal of Men's Health*, 3(2), 93-103.
- Aho, A. L., Tarkka, M.-T., Åstedt-Kurki, P., Sorvari, R., & Kaunonen, M. (2011). Evaluating a bereavement follow-up intervention for fathers' grief and describe fathers' experiences received support after the death of a child—A pilot study. *Death Studies*, 35(10), 879-904.
- Arnold, J., & Gemma, P. B. (2008). The Continuing Process of Parental grief. *Death Studies*, 32, 658-673.
- Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006) The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatic Obstetrics & Gynecology*, 27, 245-256.
- Barrera, M., O'Connor, K., D'Agostino, N. M., Spencer, L., Nicholas, D., et al. (2009). Early parental adjustment and bereavement after childhood cancer death. *Death Studies*, 33, 497-520.
- Bellali, T., & Papadatou, D. (2006). Parental grief following the brain death of a child: Does consent or refusal to organ donation affect their grief? *Death Studies*, 30, 883-917.
- Benkel, I., Wijk, H., & Molander, U. (2009). Family and friends provide most social support the bereaved. *Palliative Medicine*, 23, 141-149.
- Blackwood, B. (2006). Methodological issues in evaluating complex healthcare interventions. *Journal of Advanced Nursing*, 54, 612-622.
- Cacciatore, J., DeFrain, J., Jones, K. L. C., & Jones, H. (2008). Stillbirth and the couple: A gender-based exploration. *Journal of Family Social Work*, 11, 351-372.
- Chambers, H. M., & Chan, F. Y. (2004). Support for women/families after perinatal death. *Cochrane Database Systematic Review*, 3.
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*, 114, 1248-1252.

- Davies, R. (2004). New understandings of parental grief: Literature review. *Journal of Advanced Nursing*, 46, 506-513.
- DiMarco, M. A., Menke, E. M., & McNamara, T. (2001). Evaluating a support group for perinatal loss. *American Journal of Maternal Child Nursing*, 26, 135-140.
- Dyregrov, K. (2004). Strategies of professional assistance after traumatic deaths: Empowerment or disempowerment? *Scandinavian Journal of Psychology*, 45, 181-189.
- Dyregrov, K., & Dyregrov, A. (2008). *Effective grief and bereavement support. The role of family, friends, colleagues, schools and support professionals*. London, UK: Jessica Kingsley Publishers.
- Geron, Y., Ginzburg, K., & Solomon, Z. (2003). Predictors of bereaved parents' satisfaction with group support: An Israeli perspective. *Death Studies*, 27, 405-429.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Gudmundsdottir, M. (2009). Embodied Grief: Bereaved parent's narratives of their suffering body. *Omega: The Journal of Death and Dying*, 59, 253-269.
- Hogan, N. S., & Schmidt, L. A. (2002). Testing the grief to personal growth model using structural equation modeling. *Death Studies*, 26, 615-634.
- Kavanaugh, K., & Hersherberger, P. (2005). Perinatal loss in low-income African American parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 34, 595-605.
- Kavanaugh, K., Trier, D., & Korzer, M. (2004). Social support following perinatal loss. *Journal of Family Nursing*, 10, 70-92.
- Kitson, C. (2002). Fathers experience stillbirth as a waste of life and needed to protect their partners and express grief in their own way. *Evidence-Based Nursing*, 5, 61.
- Kreieberg, U. C., Lannen, P., Onelov, E., & Wolfe, J. (2007). Parental grief after losing a child to cancer: Impact of professional and social support on long-term outcomes. *Journal of Clinical Oncology*, 25, 3307-3312.
- Li, J., Hansen, D., Mortensen, P. B., & Olsen, J. (2002). Myocardial infarction in parents who lost a child. A nationwide prospective cohort study in Denmark. *Circulation*, 106, 1634-1639.
- Li, J., Laursen, T. M., Precht, D. H., Olsen, J., & Mortensen, P. B. (2005). Hospitalization for mental illness among parents after the death of a child. *The New England Journal & Medicine*, 352, 1190-1196.
- Li, J., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: A nationwide follow-up study. *The Lancet*, 361, 363-367.
- McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. *Sociology of Health & Illness* 26, 326-350.
- Ministry of Social Affairs and Health. (2009). Traumaattisten tilanteiden psykososiaalinen tuki ja palvelut. Opas kunnille ja kuntayhtymille. Sosiaali-ja terveysministeriön selvityksiä 2009:41 Työryhmän muistio. Helsinki 2009, 61.
- Murphy, S. A. (2000). The use of research findings in bereavement programs: A case study. *Death Studies*, 24, 585-602.
- Murphy, S. A., Johnson, C., Cain, K. C., Das Gupta, A. D., Dimond, M., & Lohan, J. (1998). Broad-spectrum group treatment for parents bereaved by the violent deaths of their 12-to 28-old children: A randomized controlled trial. *Death Studies*, 22, 209-235.
- Murray, J. A., Terry, D. J., Vance, J. C., Battistutta, D., & Connolly, Y. (2000). Effects of a program of intervention on parental distress following infant death. *Death Studies*, 24, 275-305.

- Nikkola, I., Kaunonen, M., & Aho, A. L. (2013). Mother's experience of the support from a bereavement follow-up intervention after the death of a child. *Journal of Clinical Nursing*, 22(7-8), 1151-1162.
- Oliver, R., Sturtevant, J., Scheetz, J., & Fallat, M. (2001). Beneficial effects of a hospital bereavement intervention program after traumatic childhood death. *The Journal of Trauma*, 50, 440-448.
- Prigerson, H. G., Vanderwerker, L. C., & Maciejewski, P. K. (2008). Prolonged grief disorder: A case for inclusion in DSMV. In: M. Stroebe, R. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: 21st century perspectives* (pp. 165-186). Washington DC: American Psychological Association Press.
- Qin, P., & Mortensen, P. B. (2003). The impact of parental status on the risk of complicated suicide. *Archives of General Psychiatry*, 60, 797-802.
- Raitio, K., Kaunonen, M., & Aho, A. L. (Submitted for review). Mother's grief after the death of a child—bereavement follow-up intervention.
- Reilly-Smorawski, B., Armstrong, A., & Catlin, E. (2002). Bereavement support for couples following death of a baby: Program development and 14-year exit analysis. *Death Studies*, 26, 21-37.
- Rowa-Dewar, N. (2002). Do interventions make a difference to bereaved parents? A systematic review of control studies. *International Journal of Palliative Nursing*, 8, 452-457.
- Samuelsson, M., Rådestad, I., & Segesten, K. (2001). A waste of life: Fathers' experience of losing a child before birth. *Birth*, 28, 124-130.
- Tilastokeskus. (2012). *Statistics Finland*. Available at <http://www.stat.fi/index.html>
- Turton, P., Badenhorst, W., Hughes, P., Ward, J., Riches, S., & White, S. (2006). Psychological impact of stillbirth on fathers in the subsequent pregnancy and puerperium. *British Journal of Psychiatry*, 188, 165-172.
- Webel, A. R., Okonsky, J., Trompeta, J., & Holzemer, W. L. (2010). A systematic review of the effectiveness of peer-based interventions on health-related behaviors in adults. *American Journal of Public Health*, 100, 247-253.
- White, D. L., Walker, A. J., & Richards, L. N. (2008). Intergenerational family support following infant death. *The International Journal of Aging and Human Development*, 67, 187-208.
- Wing, D. G., Burge-Callaway, K., Clance, P. R., & Armistead, L. (2001). Understanding gender differences in bereavement following the death of an infant: Implications for treatment. *Psychotherapy*, 38, 60-73.

Direct reprint requests to:

Anna Liisa Aho
University of Tampere
School of Health Science
P.O. Box 607
FIN-33014 Tampere Finland
e-mail: anna.l.aho@uta.fi