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Peer-Group Support for Bereaved Children: A Qualitative Interview Study

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Background: While it has been shown that bereaved children can experience emotional or behavioural problems, the evidence is inconclusive regarding which children would benefit from support and the kind of support to offer. This study aimed to obtain children's and parents' views on their experiences following bereavement and the usefulness of a peer-group support programme. **Method:** Thirty-nine families who had attended a community-based peer-group bereavement support programme within the previous 4 years were approached. Of the 23 with confirmed contact details, 17 agreed to participate. Qualitative interviews were conducted with 23 children (range 8 to 17 years) and 17 parents. **Results**: Children were concerned about isolation from peers and emphasized the value of meeting other children with

experiences of bereavement in the group. Parents were concerned about lack of communication within the home about the bereavement, which continued after the group. Most children and parents would have liked more support, either more groups or an ongoing link. **Conclusions**: Referral to peer-group support may have the potential to improve bereaved children experiencing feelings of social isolation and help them develop coping strategies. Other family-focused support may also be needed for some children.

Key Practitioner Message:

- Opinions differ about services for bereaved children, with sparse evidence to support any particular type of service and few studies using open-ended methods with children

- Bereaved children may withdraw from social interactions with friends from school or the neighbourhood

- Peer-group support from similarly bereaved children can provide the opportunity to shares feelings and issues openly with other children, which may enhance well-being

- Lack of communication within the home about the bereavement was not said to be improved following the group support for most families interviewed

Keywords: Bereavement; social isolation; support groups; well-being; peers

Introduction

About 20% of bereaved children are likely to show higher than expected levels of psychiatric difficulties that needed specialist services, particularly depression (Dowdney et al., 1999). Experts have debated whether counselling for bereaved children should routinely be offered, which children need support, and the most

effective forms of service (Black, 1996; Harrington, 1996; Wilkinson, 2001). Child

bereavement services available in the UK are predominantly family work (86%) or

individual child support (62%); they are less likely to be family groups (53%) or child

groups (45%; Rolls, 2007). Decisions about the nature and extent of support to offer

may be based on what is available locally, with many services provided by the third

sector (Rolls & Payne, 2003).

Making informed decisions can be problematic (Braund & Rose, 2001) and

clinicians need a good evidence base (Wilkinson, 2001) but the task of evaluating

child bereavement services is complex and ethical issues have been raised about RCT

studies (McWhinney, Bass, & Donner, 1994). Only one RCT has been conducted with

bereaved children (Sandler et al., 2003) while other attempts have failed (Croy et al.,

2004; McWhinney et al., 1994). The Sandler et al. trial, conducted in Phoenix

Arizona, compared a 12-session manualised group service to self-study of some of the

materials. Participants were solicited volunteers and outcomes were structured

questionnaires on parental behaviour, discipline, parental and child mental health

problems and coping strategies. Improvements were identified in parenting, coping

and caregiver mental health, and there were also reductions in mental health problems

for girls who had displayed more at the outset.

Evidence-based decision making is further complicated by the diversity of the

services examined in existing research, including: one to one sessions and support

groups (Sandler et al., 2003; Tonkins & Lambert, 1996; Williams et al., 1998;

Zambelli & De Rosa, 1992); residential camps (Stokes, Wyers, & Crossley, 1997);

music therapy (Register & Hilliard, 2008); and home sessions (Black & Urbanowicz,

1987). Evaluation methods are also diverse, including case studies (Zambelli & De

Rosa, 1992), qualitative interviews (Williams et al., 1998; Wilkinson et al., 2007) and

self-report questionnaires (Sandler et al., 2003; Tonkins & Lambert, 1996). Qualitative methodologies have been recommended to explore factors that may be pertinent to support (Dowdney, 2000). Post-intervention data on 'what helped' and 'what has changed' are said to be missing (Rolls, 2007).

Group work, which could be a cost effective option when resources are limited, is gaining in popularity (Sandler et al., 2003; Christ et al., 2000). Children are said to benefit from meeting others in a similar situation (Stokes et al., 1997), with reduction in emotional problems (Kitchener & Pennells, 1990; Williams et al., 1998), but most studies have not provided detailed feedback from the children themselves. The current study used semi-structured qualitative interviews with children and parents to explore the perceived impact of bereavement on children of a community-based bereavement peer-group support service.

Method

Ethical approval

Ethical approval was received from Birkbeck College School of Psychological Sciences Research Ethics Committee and then from the executive committee managing the bereavement support service. Parents first gave verbal consent on the telephone for a home visit, having spoken to children and ensuring their interest in participation. Written consent was then obtained from parents and children at the home visit. They were assured of confidentiality both in a written information sheet and again prior to signing the consent form. Jigsaw4U agreed to arrange for clinical support if any child was identified during the research as becoming distressed, though this did not occur.

The intervention

Jigsaw4U (http://www.jigsaw4u.org.uk/) is a community-based charity that offers peer-groups for bereaved families, with separate groups for children under 10 and over 10 years, and parents meeting separately. Each group is run by a paid Jigsaw staff member helped by trained adult volunteers. The ratio in children's groups is on average 1 adult: 2 children; parent groups are run either by two staff members or one staff member and a volunteer. Child group size varies depending on intake from 3-8 members. Groups take place on a week-day evening, last 90 minutes, and run over approximately 6-8 weeks, with a residential weekend in the middle. At the end of each session the leaders of children's groups give general feedback to the parent group on what the children were doing and how the session went, keeping confidential what the children were sharing.

Each child session is structured around an activity designed to open and facilitate communication and to help the participants get in touch with and express their grief. Adults do some of the same activities as the children but with more discussion and sharing of experience and feelings. Examples of activities:

1) Memory boxes: participants cut pictures from magazines and use stickers to decorate boxes to celebrate the memory of the deceased person. They are encouraged to bring something that belongs to or is associated with that person to the next session, when they share what they have put on and inside the boxes.

2) Salt jars: children and adults are asked to think of different memories and times with the person who died and give each a colour (e.g. yellow for holiday, blue for football matches, white for skiing), then rub coloured chalks into salt and pour differently coloured layers into the jar. Sharing follows.

3) Anger wall: participants make a list of things they feel angry about or write a letter, then attach it to a tarpaulin wall and are given wet pieces of clay to throw at it until their list falls down. They can scream if they wish.

4) Tesco Tantrum: modeled on children's tantrums in supermarkets, all are encouraged to lie on the carpet, think of something they are angry about, punch their fists and stamp their feet and scream at the top of their voices until they feel they have had enough.

Participants

Recruitment. Eligible families had children currently between 8 and 17 years who had experienced the death of a parent or sibling and had used the programme between January 2004 and May 2008. Families attend a minimum of 6 months after bereavement and were considered eligible if they had finished the programme at least 6 months prior to the study. To maintain confidentiality, the programme approached them by letter, with follow-up phone calls after 2 weeks. If they were interested their name was passed to the researcher who telephoned to make an appointment to describe the study and ask for written consent. Of the 39 meeting the criteria, 4 responded positively to the letter. Of the remaining 35, 19 telephone numbers were available and a further 13 agreed to participate, while 6 refused. Reasons for refusal were: wanting to move on; not re-opening old wounds; or lack of time. Thus the final group of 17 represented 74% of those with complete contact details and 44% of the identified eligible group. While modest, this compares with other studies of bereaved families. For example Sandler et al. (2003) recruited 36% of eligible families to their study. The majority without current telephone numbers had used the programme 3 or 4 years previously and may have moved to new homes. To retain complete

confidentiality no background information was made available about the families who were approached but who did not take part other than the date that they had used the programme.

Study population

Seventeen families with 25 children (15 girls and 10 boys) participated; 17 parents were interviewed (14 mothers, 3 fathers) and 23 children. At the request of their parents, two children, both 9 years old, were not interviewed. The mean child age was 12.5 (range 8 to 17). For 16 families children experienced the death of a parent (13 fathers, 3 mothers) and in one case the death was of a much older sibling. Causes of death were: cancer (7); sudden death (8; e.g. brain aneurysm, stroke, heart attack); one drug overdose and one suicide. The mean time since the bereavement was 2.7 years, with all but two between 1 and 5 years. Two of the older children had experienced the bereavement 8 years previously, but had only attended the bereavement service recently, approximately one year before the interviews in each case. The time since taking part in the support ranged from 6 months to 4 years, with a mean of 2.0 years. Systematic information about referral reasons was not made available but, based on information provided spontaneously in interviews, referrals came from various sources, including schools, social workers, local churches, or were self-referrals by parents who had heard of the support through word of mouth or by Internet search. The families were predominantly middle class or professional (12) with 5 parents in working class occupations. Three of the 17 families had minority ethnic backgrounds.

Interviews

Open-ended interviews were conducted separately with children and parents except for two families where parents wished to be present for the child interviews. All were conducted by the same interviewer (MM) who had recently received the training to be a volunteer for the programme and was also trained in the conduct of qualitative interviews. She had not taken part in the support provided to the respondents. Schedules for children and parents were developed by both authors based on existing literature and covered prompts about the same topics: school functioning; relationships with peers; emotional or behavioural problems; self-esteem; family life; and the relevance of the group support to any of these. Questions were simple so that they could be used with children across the age range and included such ones as: 'Has Jigsaw4U been helpful for the time you spend at school or with friends?' 'Has it been helpful for anything about home life?' They were asked about any other support received either before or after the groups, and their recommendations for modifying the Jigsaw4U support. All interviews were recorded and transcribed.

Analysis

Interpretative phenomenological analysis (Smith & Osborn, 2008) was conducted jointly by the authors to identify emerging themes. Transcripts were read and the left-hand margin used to identify emergent themes. Themes are modified as each transcript is read and, where relevant, clustered together. Emergent themes were discussed and refined to arrive at consensus for a final coding framework covering the impact of the bereavement and the impact of the support service (see Tables 1 and 2). A modified form of content analysis (Silverman, 1993) was then used to quantify the

presence of remarks pertaining to each theme at least once in each child and parent interviews. Given the small sample size the results are not considered in relation to child gender or child age. However, respondents are identified after quotes by: Family ID (1 to 17); the respondent (mother, father, girl, boy); and the child's age at the time of being interviewed (see Tables 1 and 2). To ensure confidentiality the child's age at the time of the bereavement is not given.

Results

Perceived impact of bereavement

Socio-emotional problems: Reflecting previous research, a substantial number of the children (18, 78%) described socio-emotional difficulties subsequent to their bereavement, noted also by three-quarters of their parents (13, 76%) (see Table 1). Anger or aggression was the most frequently mentioned problem, by both children and parents was. Depression or sadness was more often reported by children but not parents and similarly, but less often, feelings of guilt or blame were more likely to be mentioned by children (see Table 1).

Table 1 about here

Poor communication at home

Limited or no communication between parent and child at home about the bereavement was noted by almost two-thirds of the parents (11, 65%) and by just over one-third of the children (9, 39%) (see Table 1). Some parents described this as the reason they had gone to the support service. A similar proportion of parents (12, 71%) commented on the child not showing distress at the time of the bereavement, also noted by some of the children (5, 22%; see Table 1). Attempts by parents to

encourage talk could reportedly lead to children indicating that they had no wish to discuss their bereavement. Several children commented that the main reason they did not talk about their bereavement at home was to avoid upsetting the remaining parent and that they did not have strategies for dealing with the distress that might ensue.

Isolation from peers

Almost half the bereaved children interviewed said they had experienced problems with their peers (11, 48%) (see Table 1), that bereavement had left them feeling 'set apart' from peers who had not experienced the death of a family member, resulting in the avoidance of or awkwardness in social interactions: 'Part of me wanted to tell everyone but part of me didn't, just in case I got upset or made other people feel worse' (F10, girl 14). It also proved difficult when other children talked about their own families and enjoyable family events. The fact that peers who had not experienced bereavement were avoided could result in a strong sense of isolation. Withholding information from peers was not always known about at home, being mentioned by only one-third of parents (6, 35%). One mother discovered that her sons had not discussed their bereavement at school when she explained to another parent why she was asking her to give them a ride home. A small number of children (3, 13%) also mentioned that they had experienced bullying from peers after the bereavement (see Table 1).

Perceived impact of the intervention

Share experiences with peers who understand. Half of the children (14, 52%) mentioned that the main benefit of the group support for them was meeting other children who had similar experiences, which enabled them to talk more openly and

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feel less isolated (see Table 2). A similar proportion of the parents (9, 53%) also identified this as an important outcome of the group support (see Table 2).

[Table 2 about here]

Develop strategies for dealing with emotions

Another frequently reported outcome, mentioned by just under half the children (10, 43%; see Table 2), was developing strategies to deal with their emotions and being more open about their feelings regarding bereavement. Some specifically mentioned the way that it had helped them express anger, a key focus of many of the activities.

Keep a positive memory alive

Almost one-third of the children (7, 30%) mentioned that the group support helped them to think in a positive way about the deceased parent and to recall good times that they had shared, which was a particular issue for some if their parent had been ill for many years. Parents did not mention this at all.

Communicate more freely at home

Only a small number of children (4, 17%) said they talked more freely to family members after the support, and no parent mentioned this as an outcome of the support (see Table 2). If it did occur, it was perceived to be important, as illustrated by a girl who had been bereaved 8 years earlier: 'We opened up to each other a lot more, we dealt with our problems and I think are now at the same level' (F5, girl 17).

Lack of impact

Some problems were said to have continued after the six sessions had ended. The presence of ongoing feelings of anger was mentioned by two children and four parents (see Table 2).

Programme not sufficient

The need for the programme to provide more contact was mentioned by just under half the children (10, 43%) and by the majority of parents (14, 82%; see Table 2). Suggestions included increasing the number of sessions or keeping to six sessions but with the possibility of on-going contact as a 'life-line'. They wanted to be weaned off gradually, according to the children's needs and progress, rather than being linked to a programme cut-off point. Other suggestions were to have regular but more widely spaced meetings (e.g. 3- or 6-monthly) or returning for further sessions after the programme's completion. Only two families indicated that the support had been sufficient: 'I think the course was good and it wasn't too long, which is good, because you don't want to get tied down with constantly being reminded of what you have gone through' (F14, boy 14).

Discussion

The strength of this study is that young people were asked directly about their experiences following bereavement and both they and their parents appeared to appreciate talking freely. For the most part even the younger children were able to talk about their experiences, although the open-ended interview technique is more likely to elicit rich material from teenage children than younger ones.

Their descriptions of emotional and behavioural problems are not surprising in the light of previous research (Dowdney et al., 1999) and possibly also reflect the fact

that these children had aroused concern and all had been referred to support services. It is encouraging that many children reported that they developed ways of coping with these difficulties through attending the group support. Nevertheless, reducing the extent of adverse emotions was not reported as the primary outcome of the service for most of the children, some of whom had received clinical services at some point for socio-emotional problems.

The most common perceived benefit of the group, according to the children and their parents, was the social interaction with other youngsters who had experienced bereavement. These children were said to understand the thoughts and feelings being described, were sometimes able to offer good advice about coping, but most importantly, through their friendship, the children described feeling less isolated and different. This confirms the findings of studies using structured questionnaires or relying exclusively on parent report (Wilkinson et al., 2007; Williams et al., 1998). The importance of peer relationships for children's well-being in the context of other family difficulties such as parental discord is well documented (Wasserstein & La Greca, 1996) but in a circumstance such as the death of one's parent the usual peer group may not be able to provide the kind of relationship that could help a grieving child.

Children indicated that opportunities to talk to their existing peer group about their bereavement, or how they felt, were limited and they were likely to avoid social interactions with friends. This peer-group support, currently not the most frequently offered type of bereavement service for children (Rolls, 2007), provided them with the opportunity to express some of their anxieties and stresses and to talk freely with other youngsters. However, over the long-term it is likely that they will benefit from

strategies to help them re-engage effectively with other peer groups at school or in their neighbourhoods.

It is important to note the perceived limitation of group support in relation to family communication. The intervention was said not to have made much of an impact on child-parent communication about the bereavement or on children expressing distress freely at home despite many parents mentioning it as a concern; indeed, for some, the primary reason for attending the service. Black and Urbanowicz (1987) found that a favourable outcome following bereavement in terms of mental health was related to children having cried and talked about the deceased person. The activities presented in these group sessions encourage children to express their emotions freely in this relatively safe setting with similarly affected peers and they describe doing so. However, joint sessions with parents – either in groups or as families – may help parents and children express their strong emotions together. Parents described being more attuned to children's anger than to their sadness and a number of the activities focus on releasing anger. Over the long term, far more openness about a range of emotions, particularly sadness or depression, may allow parents to provide the ongoing support that their children are likely to need, and ways to foster this may have to be developed.

Most of the respondents indicated that the provision of support had been too brief and the service lacked the capacity to keep open a means of 'touching base' should a difficulty arise. Keeping to a relatively low number of sessions reflects, in part, third sector provision that is reliant on funding that may fluctuate (Rolls & Payne, 2003). A brief intervention can be made available to more children and families. However, other bereavement support is also time-limited so that the participants will be able to say 'goodbye' and gradually re-integrate more effectively

with other aspects of their lives. The remarks made by these children and parents indicated that this was sometimes a challenge.

This study has several limitations. The group is selective in that all had been referred to and then taken up the offer of group support from one particular service and, typical of other research with bereaved families (Sandler et al., 2003; Wilkinson et al., 2007), the proportion agreeing to be interviewed was less than half those eligible. Those who declined either directly or indirectly by not responding to the letter may have different ideas about the intervention. It must also be kept in mind that bereaved children are a heterogeneous group, and for many this kind of experience may not be necessary or useful. Those not referred may have different needs or be coping well without any service.

The number of interviews is small, although this is not uncommon for this type of analysis (Smith & Osborn, 2008), focussing on the perceptions and understanding of a particular group. One final limitation is the variable amount of time that had elapsed since the support, and since the bereavement. All the families were recruited from one location so it was necessary to recruit from groups that took place over several years. The respondents had varying amounts of time to process their thoughts, but this does reflect families coming to this type of service, who do not all enter the support soon after bereavement, some coming 6 or 7 years after the death. The limitations notwithstanding, this study heard from the children directly and in detail and can provide useful insights into the kind of difference that this form of peer-group support can and cannot provide. Their comments highlight the impact that bereavement can have on children's social interactions with peers. Future research might explore why family communication appeared to be relatively unaffected by this particular service and what other strategies might be more effective in that respect.

For example, peer-group support could be offered in rigorous trials as a stand-alone service or with individual and family support so that the most effective range of bereavement services can be made available for those children who need them.

Acknowledgements

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Table 1. Themes pertaining to the impact of the bereavement on the child

Major theme	Minor theme	Child total N=23	Child only	Child and parent	Parent only	Parent total N=17	Example
Socio-emotional problems		18	6	12	1	13	
	Anger or aggression	13	6	7	2	9	I got angry and took it out on people, sometimes I would start punching and kicking things. (F19, girl 9) He would just kick and punch and cry … he would lash out. (F21, mother, boy 10)
	Sad or depressed	9	7	2	1	3	I was very depressed [when she started the support] I was just getting over self-harming, I tried to commit suicide. (F5, girl 17) At home she was desperately sad … sometimes she would be very angry and sometimes she would be overwhelmingly sad and cry (F15, mother, girl 16)
	Guilt, feel to blame	4	4	0	1	1	Guilt is like finally realising something is gone. And it's like you want to say sorry that you couldn't have done anything about it… like you were meant to do something about it (F10, girl 14) I found it difficult when she died, I blamed it on myself (F10, girl 11)

							He said to me 'Mummy, Daddy had these dizzy spells, would he have died if I had told you?' ….I think he holds guilt for not telling me (F20, mother, boy 12)
Little home communication		11	3	8	8	16	
	No talk of deceased or bereavement at home	9	4	5	6	11	I never knew what to say to her (F12, boy 14) The reason we went to [support service] was that the children weren't talking about anything to do with their mum, not even a passing comment (F13, father, boy 8 and girl 11) [When I start a conversation] he will just walk out of the room or doesn't say anything or tries to keep busy with something different (F8, mother, boy 12)
	Not show distress	5	2	3	9	12	I didn't really cry before, I didn't talk about it much (F1, girl 11) My mum used to get very upset and cried if we mentioned dad so I did not want to upset her (F5, girl 17) He said nothing at all, not talking, not crying (F8, mother, boy 12) She kept a lot in, she didn't cry very much, I think because she saw me keeping it in (F20, mother, girl 9)
Isolation from peers		11	6	5	1	6	

	Feel different from peers	6	4	2	0	2	I felt really alone, because when it happens you feel like you're the only person it's happening to and I didn't feel like anyone else was going through the same thing. No one else was able to understand (F14, boy 14) You kind of have those raw emotions in your head …you think no one understands you…. you feel really lonely (F15, girl 16)
	Not talk to peers	5	3	2	1	3	When my dad first died they didn't know how to talk to me because they thought I'd get all upset….so I felt quite uncomfortable when I went out with them [friends at school] (F4, boy 14) Everyone tried not to talk about it but sometimes when people talk about their dad I find it hard (F21, girl 14)
	Bullying, related to bereavement	3	2	1	1	2	My Mum saw that girl grab onto my shoulders, pushing me to the floor and say 'your dad is dead, you've got nothing' (F5, girl 17)

Table 2. Themes related to the perceived impact of group support

Theme	Child Total N=23	Child only	Child and parent	Parent only	Parent Total N=17	Example
Meet/share experience with peers who will understand	14	11	3	6	9	People in the group were in the same situation as you, so you don't feel uncomfortable about talking about it or being there… they all know how you feel… you are not the odd person out (F10, girl 14) It was good because I met a lot of people who have gone through the same experience so it helped a lot; it makes you feel less left out (F21, boy 10) She made a couple of friends, someone she could talk to, who understood what she was going through, it's not the same as talking to a parent. She was in a group of people who were in the same boat (F7, father, girl 9).
Cope with/express feelings better	10	8	2	0	2	It made you feel like you were genuinely having fun but you were actually letting out your feelings as well, which you didn't realise you were doing (F9, boy 15) Instead of pushing them away (emotions) you can release them in a healthy way (F15, girl 16) I liked the anger wall…. I got out all my emotions, throwing mud at the wall, all my anger (F1, girl 11)
Keep positive memory alive	7	7	0	0	0	They taught me about different ways to remember him, and how to deal with birthdays and anniversaries, and special holidays, whereas before I was pretty stuck (F22, girl 16) We did games and activities and they help you to remember the good times you had with your dad (F9, girl 14)
Communicate more freely with family	4	4	0	0	0	After [the group support] I started talking to Mum about it (F1, girl 12)

Lack of impact	2	1	1	3	4	For the crying it [the support] helped a lot because I was crying constantly before, and knowing that I'd be able to talk about that was helpful, with the anger I'm not too sure really (F22, girl 16) He worries me, I can't put my finger on it, he's just more angry; I wonder why he isn't coming out of that… I often thought he needs more help [had counsellor who moved away] (F21, mother, boy 10)
Programme not sufficient	10	1	9	5	14	I thought I should have been twice a week, then you could get more time into six weeks themselves, and instead of six sessions, 12 sessions (F9, girl 14). It was after it finished that she… grieved, because it has gone. I felt it was far too brief for her. And she said she was quite angry it had finished (F19, mother, girl 9) My only criticism of it is that when it's over, it's over, end of the story. They have parties occasionally, but to be honest [son] never wanted to go to them. So it's quite a shame that there's no internet link (F12, mother, boy 14)