

Views about support for bereaved children

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What will be covered

- Themes emerging from:
 - Qualitative interviews with parents/caregivers who had been involved with hospices for cancer patients and who had either accessed or turned down support for their child, and interviews with bereavement counsellors
 - Qualitative interviews with children and parents who had experience of a community-based family support service post bereavement
- Conclusions and suggestions for future research

Hospice study

- Developed after failure of an RCT; staff tended to be protective and parents approached mainly had firm views - either did not wish to be randomised as they either expected support to help, or would not want support
- Decision to look in more detail at perceptions of support (pro and con) and of experiences if the offer was accepted

Participants

- Parents whose child (aged 4 to 18 years) had a parent, grandparent or sibling who had died in one of seven hospices around the UK. Those recently bereaved (>6 months) were not approached
- Interviews with services users (19) and those contacted but decided against the support service (6)
- Interviews with counsellors (6) involved in providing support

What was offered

- Practitioners mainly counsellors or social workers
- All seven hospices had contact with the families prior to bereavement, all offered telephone support, and work with individual families or children. Two were also offering group support and two had offered groups in the past.
- In four hospices volunteers worked with professionals.
- Five of the seven hospices had regular contact with schools

Why the service was used

- Five themes identified by parents
 1. Advice and reassurance - Am I doing it right?
 2. Communication problems
 3. Parental grief, not able to support child emotionally
 4. Behaviour problems
 5. School issues – fitting in, not involving teachers

Some comments to illustrate

Advice: *I think we were looking for [counsellor] as a person to say “yes you’re doing the right thing*

Communication: *She offered an outlet for the children to express their feelings, that they maybe felt uneasy sharing with me, due to concern for me and not wanting to upset me*

Parental grief: *I give them basic support, roof over their head, hot meals, clean clothes... but I don’t think there is anyone there for them emotionally... I’m not emotionally strong enough*

More comments

Behaviour problems: *I had to try and work out what was grief, what was normal teenage aggression, what was anger from her mum dying, and anger with me*

School, fitting in: *How much one should make it a school's business, or anybody's, I don't know?*

Her friends actually got quite jealous of the fact, of the attention that she was getting. They didn't understand really, yes she was getting a lot of attention, but it was for the wrong reasons

Reasons for not using the support

- Two main reasons

1. No overt sign of distress

I think if I'd have felt that their grief wasn't moving on, then yes, I would [have used the service]

2. Might cause distress

We didn't know if it would shock him too much, because we couldn't really understand what he was thinking anyway, we didn't want to plant anything in his mind, so we thought we'd go with the flow

Counsellors

- Gave very similar reasons for accepting support
- Additional reasons for not accepting
 1. Preconceived views about counselling

Child said to her “Are you a social worker? Because if you’re a social worker I don’t want to talk to you”
 2. Fear of loss of control

Parents don’t like to think they can’t cope

Perceptions of the support

- Valued accessibility and staff flexibility

It was like a Mary Poppins kind of thing... I could ring up at any time of day and ask questions ...just to know that that was there was fantastic

- Perceived as a safe environment, able to talk in confidence, away from family

He is able to open up in a very different way to the way he would if I was present

- Group reduced social isolation

For ages, mine were convinced that they were the only children that this had happened to

- Need feedback: parents wanted information about what was discussed

I was needing feedback about things she couldn't tell me so that I knew what I was doing wrong

I have this jar on the mantelpiece[after 12 months].... I'd like to know why they were doing it because there must be some reason why they do these activities

Group based family support

Participants

- Families with child aged 8 to 17 years who had experienced death of a parent or sibling
- Had used the support over a 4 year period (excluding those still using the service)
- Approached first via the charity by letter, with follow-up telephone calls if number available
- Of those definitely contacted (N=23) 17 agreed, those who refused mainly wanted to 'move on'
- Interviews with 17 parents and 23 children

What was offered

- Community-based charity
- Offers peer groups for bereaved families with separate groups for children up to 10 years and over 10 years
- Parents meet separately in a parent group. Child group leader gives general feedback to parents at the end of the session
- Groups run by a charity employee and a volunteer, or by two employees
- Take place on a week day evening, for 90 minutes, over 6-8 weeks with a residential weekend in the middle
- Child groups are structured around an activity designed to open and facilitate communication; adults do some of these activities but with more discussion

Perceived impact of bereavement

- Socio-emotional problems
 - Anger or aggression
 - Sadness/depression
 - Guilt/blame
- Poor home communication
 - Not mentioning deceased family member
 - Not showing distress
- Isolation from peers
 - Felt different/set apart
 - Peers did not know how to talk about bereavement
 - Experience bullying related to bereavement

Some children's comments

I got angry and took it out on people, sometimes I would start punching and kicking things (girl, 9)

I was very depressed [when she started the support] I was just getting over self-harming, I tried to commit suicide (girl, 17)

I found it difficult when she died, I blamed it on myself (girl, 11)

I never knew what to say to her [his mother] (boy, 14)

My mum used to get very upset and cried if we mentioned dad so I did not want to upset her (girl, 17)

*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.
(boy, 14)*

Everyone tried not to talk about it but sometimes when people talk about their dad I find it hard (girl, 14)

Mum saw a girl grab onto my shoulders, pushing me to the floor and say 'your dad is dead, you've got nothing (girl, 17)

Perceptions of the support's impact

Parents and children

- Able to share experiences with peers who will understand

Mainly or only children

- Cope better at home with expressing feelings
- Keep a positive memory alive
- Communicate more freely with family (but not mentioned by many)

Value of group - Shared experience

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. (Father of girl, 9)

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. (boy, 10)

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 (girl, 14)

Activities help with emotions

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 (boy, 15)

I liked the anger wall.... I got out all my emotions, throwing mud at the wall, all my anger (girl, 11)

Instead of pushing them away (emotions) you can release them in a healthy way (girl, 16)

Memories and family communication

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 (girl, 16)

We did games and activities and they help you to remember the good times you had with your dad (girl, 14)

After [the group support] I started talking to Mum about it (girl, 12)

Families would welcome more support

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(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 (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. So it's quite a shame that there's no internet link (mother, boy 14)

Conclusions

- Many families welcome the idea of support although they can also act as gatekeepers, reluctant to get support for their child
- Parents decide on the necessity for support partly based on overt signs of distress so may miss internalising problems such as anxiety or depression
- Group interventions are perceived positively by parents and children

Conclusions continued

- Support may be particularly beneficial if offered separately to children and parents, but parents need some general feedback
- Children may not be able to communicate with non-bereaved peers, and do not want to be 'different'. Peer group support provides an important opportunity to share feelings and thoughts safely
- Despite acknowledgement that poor home communication was a problem, few children reported that it had improved

Possible future research directions

- Explore the best way to help family communication
- Explore in more detail what role schools could/should take
- Explore how to maintain confidentiality for children (good to provide support separate from parents/caregivers) but at the same time help parents to be involved
- Investigate what support is most effective for children with different kinds of bereavement (unexpected versus after long illness of parent/other family member)

For more information

Wilkinson, S., Croy, P., King, M. & Barnes, J. (2007) Are we getting it right? Parents' perceptions of hospice child bereavement support services. *Palliative Medicine*, 21(5), 401-407 (Also more detailed report to funders available on request)

Metel, M. & Barnes, J. (2011) Child and parent perceptions of peer-group support for bereaved children: a qualitative interview study. *Child and Adolescent Mental Health* 16(4), 201-207