Supporting children and families facing the death of a parent: part 2

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Abstract

Aim: To report on the views of children, parents and key stakeholders of a new bereavement support service for families where a parent is dying from cancer.

Study design: A qualitative pre- and post-intervention evaluation design was used. Case study methods allowed multiple perspectives to be accessed so broadening the scope of the evaluation.

Sample and setting: A purposeful sample of six families was recruited from the community palliative care service. Each case study comprised a family, a health professional and the family support worker. Six key stakeholders also contributed data.

Methods: Data gathering included individual and family group interviews, non-participant observation and interviews with nominated health professionals, key stakeholders and the family support worker. Analysis of pre- and post-intervention data were supported by QSR NVivo.

Findings: Children and families with complex and/or enduring needs benefited from the specialist expertise and interventions provided by this service.

Conclusions: Risk assessment procedures should be used to identify need and ensure limited resources are directed appropriately. Many children and families can be supported within the community drawing on their own social networks.

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This is the second of two linked articles (Kennedy et al, 2008) which report aspects of an evaluation of a new bereavement support service established in Scotland in 2005. The service was established to support children and families where a parent is dying from cancer and initially was funded for two years by a major UK cancer charity, Macmillan Cancer Support (MCS). MCS also funded the external evaluation reported here. The aim of this article is to report the views of children and parents who accessed the service and of key stakeholders associated with the service. It will describe the research methods used in the evaluation and offer recommendations for service providers.

Methods

This study was conducted within a pre- and post-intervention evaluation design using case study methods. Data were generated by a series of in-depth interviews and non-participant observations.

Aims of the evaluation

The aims were to explore the impact of the service on recipients and elicit key stakeholders' perspectives of the need for and impact of the service and to make recommendations for future service developments.

Design

A qualitative pre- and post-intervention evaluation design was selected in order to explore the experiences of families with children facing the death of a parent and the expectations that they, and the stakeholders, had of the service. Post-intervention data gathering allowed evaluation of the extent to which the service had addressed needs and met expectations. Qualitative evaluation research methods were used as these are suited to answering questions about client and community needs, the nature of services and how well these needs are being met. Methods selected for this study allowed service delivery contexts and divergent views and perspectives to be accommodated (Anastas, 2004).

The use of case study methods within the design supported inclusion of data from multiple sources. This offered a deeper understanding of the ways in which the service operates to help families cope with the catastrophic circumstances they faced. Case study methods are particularly relevant within palliative care where complex and multi-faceted services need to be understood in context (Walshe et al, 2005; Payne et al, 2007). In line with

Table 1. Participants and data gathering

Data set 1	Stakeholder interviews (6)	• Manager of palliative care service • Family support worker (FSW) • GP and Chair of the Cancer Network • Funding body manager (Macmillan Cancer Support) • Lead palliative care consultant • Previous user of children and family support service
Data set 2	Case study interviews (six families)	• Individual or group interviews held with participating family members • Pre-intervention interviews at point of referral • Post-intervention interviews after at least five interventions with the FSW
Data set 3	Case study interviews with FSW	• Pre-intervention interviews held after the FSW's first • assessment visit with each family Post-intervention interviews after FSW had had at least five interventions with each family
Data set 4	Case study interviews with nominated health care professional (HCP)	• Pre-intervention interviews held at point of referral to the new service • Post-intervention interviews after FSW had at least five interventions with each family
Data set 5	Role review interviews	• Interviews to explore elements and working of current role potential for development held with FSW • FSW's line manager • Manager from funding body
Data set 6	Observation events	• Multidisciplinary case conference • Observations of home visits • Observation of FSW visit to nursery and meeting with staff • Interview with nursery manager

Total number of interviews = 52
Total number of observations = 4
Data sets for analysis = 56

case study methods, data gathering and analysis involved triangulation of samples and methods (Yin, 2003). Six families participated in this evaluation representing differing family configurations and challenges and offering a range of ages of children and young people.

Data gathering included individual and family group interviews and non-participant observation where the researcher observed the FSW's interventions with families and then discussed them with her. Interviews were also held with identified health care professionals (HCPs), key stakeholders and the FSW. Service-related statistical data and documents, local and national reports, guidelines and key literature all fed into the evaluation (Yin, 2003).

Sample
A purposeful sample of six families was recruited to the study (Denscombe, 2003). Five families were recruited by a specialist community palliative care nurse and one by a GP. Each 'case study' comprised

a 'family' with parent/s and children up to the age of 19, a HCP identified by the family as key to their care and the FSW who delivers the service to the family.

Data gathering
Pre-intervention interviews were held with family members just after they had been referred to the service but before they had met with the FSW. Post-intervention interviews were held after family members had been on the caseload of the FSW for at least three months and had also received at least five face to face interventions. The nominated HCPs were also interviewed at these time points. Interviews with the FSW took place after the first assessment visit and again after three months or a minimum of five interventions with the family.

Focused interviews were also held with the FSW, her line manager and the funding manager from MCS. These interviews were held nine months after establishment of the new service. Separately from this six single interviews were held with

Theme 1: thrown into chaos

Theme 2: lost in the panic

Theme 3: holding them steady

Theme 4: journeying together
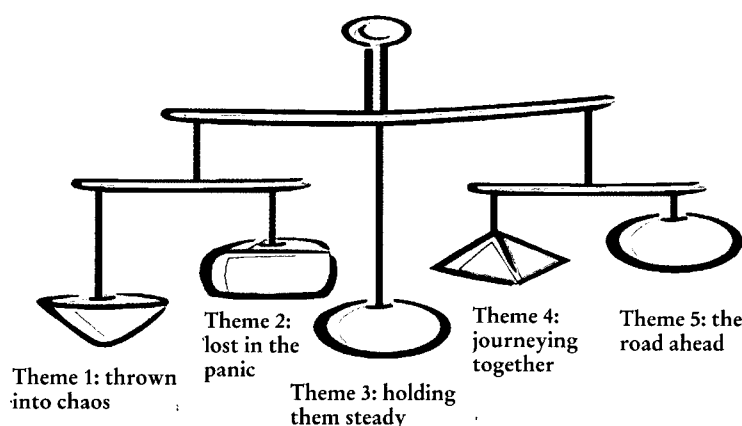
Theme 5: the road ahead

Figure 1. Mobile as metaphor

key stakeholders (*Table 1*).

Ethical issues
A study of this nature that includes profoundly vulnerable children and families has significant research governance implications and this study was conducted in line with approved guidelines (Royal College of Nursing (RCN), 2004). Normal disclosure processes that operate within Scotland were applied to the researcher (www.disclosures.co.uk). Ethics approval was sought from both the local research ethics committee and Napier University.

The researcher was experienced in end-of-life care and in researching with families facing death of a member. Younger children were seen in the presence of the parent. Two teenage children opted to be interviewed alone. This was agreed by the parent. Access to families was negotiated through the health care professional making the referral to the service and the introductory letter made it clear that they had the option to opt out without prejudice to care. Participants received written and verbal information and gave written consent at each stage of the data gathering. In recognition of the vulnerability of the participants courtesies such as thank you letters and expressions of condolence were sent as appropriate.

Approach to analysis
Analysis was supported by QSR NVivo analysis software and began with a structured approach that involved an initial sorting and coding that made the data more accessible for subsequent, and deeper, analysis and interpretation (Marshall and Rossman, 2006). Each individual family became the central focus of enquiry and each case study produced an amalgam of data which constituted a unit of analysis in its own right. Using both 'within case' and 'cross case' analysis provided a fuller, more rounded, interpretation and enhanced the overall scope of the analysis (Yin, 2003).

The conceptual framework used for analysis and reporting (*Figure 1*) represents an amalgam of key messages from the data, family systems theory, and the researchers' backgrounds in family focused research (Kissane and Bloch, 2002). This conceptualization was also informed by the early work of Skynner in 1979 (McIntyre and Lugton, 2005) who described the delicate, dynamic balance that can exist within the family system as follows:

'Visualize a mobile with four or five pieces each gently moving in the air. The whole system is in balance...a breeze catching only one segment of the mobile immediately influences the movement of every piece...the pace picks up with some pieces unbalancing and moving about chaotically for a time. Gradually, the whole exerts its influence on the errant parts but not before a decided change in direction of the whole may have taken place.' (McIntyre and Lugton, 2005)

Thematic findings
The five themes that emerged from the analysis (*Table 2*) were derived from the participants' data and reflect the words they used. Data reported under each theme represent verbatim quotes from study participants.

Theme 1: thrown into chaos
The distress and disorder that can result from serious illness were challenging for all family members. The profound disruption, bordering on chaos, to normal family life that accompanied the parent's serious life-limiting illness was evident. For seven-year-old Jason (case study one) the disruption was particularly terrifying as he faced serious illness in his lone parent. This is illustrated in the quote below:

Table 2. Thematic framework

Themes	Sub-themes	Main focus of findings
Thrown into chaos	Crisis of illness Family in turmoil Routines abandoned	Impact of illness and impending death on: patient, partner and children roles, relationships and family life
Lost in the panic	Kids out of the loop No one to turn to Crying for help	Focus is wholly on ill parent Kids protected/excluded; needs go unmet Behaviour disrupted/relationships suffer
Holding them steady	Family as focus Specialist skills Working together	Family as focus of care Family assessment: agreeing a plan Key interventions with family members Resources for supporting children and family
Journeying together	Preparing to face it Travelling together Remembering together Saying goodbye	Take it gently, adapt the pace, stay alongside Shared understanding and mutual support Capture the person/preserve positive memories Involve the family in rites and rituals Advocacy/brokering to reduce family tension
The road ahead	Riding the storm Seeking a balance Glimpsing a future Securing the legacy	Support for family during their sorrow Seeing positive aspects of past relationships Able to care for self and other family members Can see and plan beyond tomorrow Long-term negative impacts reduced

'He won't sleep in his own room. He's got to be beside me. And I've tried and tried and tried. At one stage he wouldn't let anyone go out of the house because he was frightened of losing anybody.' (Paula, mother)

Although just seven years old, Jason felt that he was responsible for his mother's care and safety. During the researcher's visit to the family home he was noticeably vigilant about his mum. Paula had a Hickman line in place and, presumably, to make things simple and understandable to a child, the Hickman line had been described to Jason as a 'pipe'. However, in his limited experience, pipes were hard and rigid, and therefore could be potentially damaging to his mother's body. The quote below shows his thinking on this:

'Well, the problem is, how could that pipe go into the vein? I have to try and stay up all night making sure she doesn't get hurt [by the pipe]. I don't even get to sleep for a long time...I stay up all night. I'm watching your pain [said to mum]. I only get like an hour's sleep...If it's going in the vein [the pipe] it's going into her heart. And that's the problem...' (Jason)

A teenager struggling to cope was 15-year-old Josh (case study five) who faced the prospect of losing both parents to illness. The text below is from research notes following a challenging interview with Josh as his communication skills were limited and responses were mainly monosyllabic or sniffs and shrugs:

'When I asked Josh what he most needed help with he said it was his behaviour. There is no doubt that Josh was heading for serious trouble with both the police and school authorities. When I asked him what he thought had caused his behaviour problems he said that he was worried about his Mum and Dad and wanted to stop thinking about it and that was his way of stopping thinking about it.'

Data confirmed that at the point of referral, participating family members were profoundly distressed due to the impending death of the ill parent. The physical and emotional manifestations of the illness can be all-consuming for parents and can lead to children's needs taking a back seat.

Theme 2: lost in the panic
Across all of the case studies there was evidence that parents struggled to reconcile the competing claims being made upon them from their sick partner and their children. In such circumstances, children had either to be dispatched elsewhere for care and attention, or had to grow up too fast; or in the case of teenagers had to

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pull back in their demands on the ill and caring parent.

The potential impact on the family is illustrated in case study two, where two-year-old Laura was often sent to her grandmother's home, limiting the time she could spend with her father:

'Karen [mum] wants to balance the scales. At the moment, she's having one or the other [husband or child]. She's not working with both. Bill [patient/dad] is paying the price in not seeing his daughter. And that's lost time. Valuable time they need together as a family unit. And if she [Laura] keeps being taken away from her daddy she'll always remember that. And that will have a lasting effect on Laura. That's where the FSW's knowledge and experience [are] invaluable to bring them back together as a family unit.'

'She [child] was being sent away to her Grandma's...that was difficult. Whereas latterly...the whole family were brought together by the service. We needed that service to bring everybody together.' (Specialist community palliative care nurse)

Manifestations of distress experienced by teenagers may be different from the younger children, but the fear and isolation felt by 17-year-old Fiona (case study three) is evident in the quotes below:

Fiona: 'I would have been right off the rails without her [FSW]. I certainly wouldn't still have the friends I have now. I think for teenagers our age, like especially between 16 and 17, you're so scared, you're moving out to the big bad world and you kind of get that little chip on your shoulder...and you feel like you're not wanted...'

FSW: '...she's talked about some of the things she's done in the past to herself which are about guilt and shame. She struggles with her sense of self and her identity, as all teenagers do...her self-esteem has been very low at times...she's a bit vulnerable to having very poor self-esteem, feeling very unworthy as a daughter to this man.'

'I asked Fiona if she ever talked to her mum and dad about how she was feeling,

but she said no she hadn't because she felt that her dad needed to have the time that was left to him to be "pleasant and as light as possible". She said, "I don't want to get heavy around Dad." She felt she couldn't talk to her mum as her mum's already coping with more than she [Fiona] is.' (Research notes)

It was found that children and teenagers often had unmet needs for support as parents struggled to meet the challenges of the terminal illness. At this point the FSW worked closely with parents to help them find ways to include and support their children.

Theme 3: holding them steady

The FSW begins her work with each family with an initial assessment visit aimed at establishing the main problems and needs, and agreeing a tentative plan with the family. Ongoing assessment is central to the service and goals can shift to meet changing priorities. In the quote below, the HCP involved in case study one identifies the value of the family approach which she feels is key to the service:

'For a child your safe haven is always the family unit, and the parent, and I think for Paula [Jason's mum, case study one] it would be so important for her to know what she needs to do. I don't think she needs that much instruction. Just to have the support from somebody [the FSW] who'll say, "You're doing the right thing. This is what you can try. This is how you can discuss it with him. This is what you can read." Just to empower her to help [her child].' (HCP)

Getting support in place for 15-year-old Josh (case study five) involved the FSW working in close liaison with the school and local police so they understood Josh's circumstances and needs. Arrangements were made for Josh to attend a support group for young people with an ill parent. The support worker's activities were directed at taking pressure off the various family members as all were severely challenged and stressed. Below, the specialist nurse gives her view of how the service worked for Josh and his family.

'I think young Josh would have gone right off the rails completely. He has

'The value of having an identified person to co-ordinate and take overall responsibility for supporting the family through their loss was apparent from the interview data'

already been in trouble with the police. I know she [FSW] can't perform miracles, and it's a heck of a big challenge! But hopefully it's made Nan and Jack talk to Josh and the rest of the family. That boy would have probably, been in somewhere by now [young offenders' institution]. And he still might but let's hope not. At least he's in the system now.' (HCP)

Families appeared to benefit from some form of 'crisis intervention' to stabilize and support them.

The FSW was at this stage engaged in reuniting the family as a unit and in helping parents to mobilize their own and their children's coping resources. The value of having an identified person to co-ordinate and take overall responsibility for supporting the family through their loss was apparent from the interview data.

Theme 4: journeying together

In 'journeying together' the focus is on bringing the family to the point where they can prepare together for the death and they feel able to say goodbye to and support each other.

In case study six, interventions focused on facilitating Eddie, Kate and their children through the final stages of Kate's illness. Eddie was about to become the lone parent of three children. In the quote below the FSW describes her work with this family.

'Well they were certainly complex but they were very willing to work with me...When I first went in, I thought there was very little time, and I was hoping to get to the point where they could have some intimacy and share some love together before she died. And, yeah, just to get to the point where Eddie could journey alongside Kate in her dying. I think we did achieve a greater understanding of the way that the past was impacting on the present.' (FSW)

Surviving family members have the bereavement to face and will ultimately need to reconstruct their lives so as to accommodate a future without the dead partner or parent. The FSW used complex and specialist skills to help them communicate and plan for the impending death. She also was instrumental in

supporting family members to preserve positive memories of the dying parent and their relationship using a number of strategies including memory boxes.

Theme 5: the road ahead

Data presented under this theme illustrate the impact and the longer-term outcomes of the service as perceived by the research participants.

'I can see the long-term benefits...really beneficial for Laura because there's bits we can tap into now but there's other bits we'll keep tapping into as she gets older...We've still got a good bit to go but the way we're treading along that road it's at a good pace, and it's with a better spring in our step and a lot more happiness... [than I had thought possible].' (Case study two surviving parent)

The extract below offers an example of the brokering work that the FSW often engages in when working with families in this situation. Keeping this family stable and united through the trauma of the illness and death of the mother was the priority.

Eddie: 'Without that service I think there would have just been a massive explosion in the house. I really really do.'

Researcher: 'And the outcome of that might have been what?'

Eddie: 'Kids everywhere [hands thrown upwards]. Towards the end, as I said Kate tried to push me away...She didn't want any of us to see her on some days...And it was sore. Me and Kate would have an argument and then she [the FSW] would come round and then that night it would just all be cuddles and we were back to normal. She helped us a lot. And I don't know if we'd have lasted through it all without the help that she offered.'

The FSW used skilled interventions before, during and after the death. Bereavement support was provided for as long as the FSW felt that the family required it. Throughout, the FSW liaised with a range of agencies such as schools, nurseries and the police. She employed a diverse range of skills, knowledge and

'For many children, especially teenagers, face-to-face counselling may not be the preferred option for support'

resources to help them to interact with and support distressed children.

Stakeholders' interviews

The stakeholders' data were drawn from senior health professionals or managers and all had a particular interest in the service. These data were less emotionally laden than family generated data, with the focus being mainly on the workings and the management of the service. Stakeholders said that they felt that the service was responding to an established need within the area. Issues raised included access to the service and the often long-term involvement of the FSW with families, and the consequent effect on her ability to take on new families, transferability and the 'long-term sustainability' of the service were raised. However, there was consensus that the service served the needs of clients very well, providing skills and time to address complex needs which they themselves did not possess.

Discussion

From the feedback provided by the children, families and stakeholders it emerged that clear strengths of the new service are its holistic, 'family-focused' approach and the skills and expertise of the FSW. Those who used the service valued it highly and fully endorsed it. A unique aspect of this service is the support provided before and during the parent's death as well as during bereavement. Parents who experienced the FSW working directly with them in supporting their children helped them prepare their children for the death and to preserve positive memories of their relationship with their dying/dead parent. These findings support existing evidence that providing support for children facing parental death could help militate against enduring negative health consequences of unresolved grief (Schurman, 2003; Chowns, 2005; Krauss, 2005).

Delivering this service required complex skills and expertise at an advanced level. This included using the principles of family therapy such as family meetings and facilitation of family dialogue in the lead up to the death (Kissane and Bloch, 2002). It was evident from this study that these approaches met the needs of the families in the study and that the level of satisfaction with the service was very high. Also appreciated by the families was that

alongside the anticipated advice and counselling activities, the FSW was involved in establishing contact with schools, police, housing authorities and even funeral directors.

Arguably, given the highly developed and all-encompassing nature of the role, and the complexity of the interventions offered, it is questionable whether others such as GPs and specialist nurses could offer a service with this level of expertise and time commitment. However, in view of the risks associated with the provision of specialist support to families in terms of creating dependency and blocking other more general sources of support, consideration needs to be given to strengthening the ability of agencies routinely in contact with families, such as teachers and general practitioners, to support families facing the death of a parent as a result of cancer or any other cause.

Moreover, the FSW's heavy clinical workload limited her capacity to share her knowledge and expertise with others. In the face of this high-calibre service it is possible that other professionals may judge their own contribution to bereavement support to be sub-optimal in circumstances where their skills may be adequate or could be developed to meet the needs of many families as not all may require the specialised help that this service offers. For most bereaved children brief interventions will meet their needs (Monroe and Krauss, 2005). Health, social, pastoral and education professionals and volunteers can also be prepared to support children with less challenging requirements.

This is not to say that the advanced skills of the FSW are undervalued. The resources of the specialist bereavement support service should, however, be directed at supporting those identified as having complex needs and requiring specialist interventions. For many children, especially teenagers, face-to-face counselling may not be the preferred option for support. Alternative approaches, such as telephone helplines, web-based support or text messaging may be preferred (Stubbs, 2005), and need to be explored and evaluated.

Limitations

This evaluation reports on a finite phase in the life of what is an evolving service. Additionally, during the evaluation

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period, a lone practitioner delivered the children and family support service which was a new development from the existing bereavement service. Purposive sampling and referral to the study through service providers who acted as gatekeepers may have excluded other families who were not referred to the specialist services or where the diagnosis was other than cancer.

Conclusions and recommendations

The findings of this evaluation study are drawn from 52 in-depth interviews and four observation events. We therefore judge the conclusions to be robust and trustworthy and well supported by data from users and stakeholders.

Every bereaved child, no matter what the cause, will require support. The nature of such support will vary according to needs and circumstances. Due to funding provision the focus for this service is on children and families where a parent is dying from cancer.

Even when restricted to cancer-related death this study demonstrated the diversity of need and the unique circumstances that each family faces. Support needs will differ in situations such as sudden and/or traumatic death and families may require different interventions and resources to support them.

Whatever the circumstances, the key to providing appropriate support lies with adequate risk assessment procedures to identify need, and ensure limited resources are directed appropriately. Many families can be successfully supported within the community drawing on their own social networks. Also, teachers, chaplains and volunteers who regularly work with children can be equipped to support them through their loss. Bereaved children and families who are identified as having complex and/or enduring needs will benefit from specialist expertise and interventions such as those provided by the service evaluated here.

In light of these findings it is evident that cross-agency working should be a key feature of future bereavement service development. A wider menu of support options should be clearly signposted drawing on national organizations that provide web-based and telephone support

for bereaved children and teenagers. Such support could benefit those young people who may prefer anonymity and to be in control of sensitive communication.

Bereavement support needs to be integrated into mainstream services and policies for young people. For families requiring intensive support, the service model reported here offers an excellent example of an holistic, family-focused service that meets complex needs and helps children and families cope with the loss of a parent. **IPN**

Key words

- Bereavement
- Children
- Family
- Evaluation
- Case study
- Palliative care

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