



Childhood
Bereavement
Network



National Children's
Bureau



Preparing the way

Evaluating support for children and young people
before the death of someone important to them

Executive Summary

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The Childhood Bereavement Network

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK. We underpin our members' work with essential support and representation: bringing them together across localities, disciplines and sectors to improve bereavement care for children.

Collectively, we share a vision that all children and young people in the UK, together with their caregivers, can easily access a choice of high quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

www.childhoodbereavementnetwork.org.uk @CBNtweets

Part of the NCB family

We are proud to be part of the National Children's Bureau (NCB), a leading national children's charity working to build a better childhood for every child, by championing their right to be safe, secure and supported.

Along with other specialist interest groups and networks such as the Anti-Bullying Alliance and the Council for Disabled children, we operate under NCB's charitable status and are based at their London headquarters.

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Acknowledgements

This report draws on the expertise and research of many dedicated professionals. They were only able to develop their expertise or generate new findings because children and families facing the most stressful and challenging of times – the likely death of a family member – were willing to reach out for help and in some cases to participate in research studies. I am grateful to each of them for what they taught the practitioners and researchers they met, and to the professionals themselves for sharing these insights for the benefit of other families.

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Executive Summary

What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.

Shortlisted priority
Palliative and End of Life Care Priority Setting
Partnership (2015)

Around 24,000 parents of children under 18 die each year in the UK (Childhood Bereavement Network, 2016), with between 60 and 75% of these deaths being expected (End of Life Care Intelligence Network 2011). Over 10,000 babies, children and young people under 25 die each year, many leaving siblings (Child Bereavement UK 2017).

The death of a close family member is associated with a range of poor outcomes for children and young people both in the short and medium term and into adulthood, including early mortality, mental and physical health problems and disrupted education (Penny and Stubbs 2015). For children bereaved of a parent through cancer, the time before the death is particularly stressful (Siegel et al 1992).

Over the last three decades, a range of services have developed across the UK to respond to bereaved children's experiences and needs (Rolls and Payne 2003, 2004; Penny 2011). An increasing number of services are also offering support to children before a death, where this is possible.

Evaluating support

The practice context

However people engage with services for children before or after a bereavement, as funders, managers, actual or potential service users, they have an interest in understanding whether it 'works'.

A survey of post-bereavement services found them to be struggling with demand for evaluation information from a range of

sources. The most common form of evaluation was post-intervention user satisfaction surveys with self-completion forms. Collection of basic data was patchy, and evaluations of processes and outcomes were less common (Rolls and Penny 2011).

To overcome the complexities of evaluating this work, Rolls (2007) recommended that the sector work together to develop a common core routine evaluation package that could be used across all services, comprising a basic dataset, user satisfaction survey and focused clinical outcomes measure. This collaboration has been taken forward by the Childhood Bereavement Network (CBN) and the package is now in use in 25-30 services.

Throughout the project, CBN members asked if the package could be adapted for use in services supporting children before a death.

The research context

This call from practice was supported by recommendations from research into interventions of support for children facing serious illness in the family, which found that while qualitative evaluations were generally positive, the quantitative evidence was limited in scope, mixed in quality and inconsistent in results (Spath et al 2007, Prchal and Landolt 2009; Niemela et al 2010; Kuhne et al 2012; Hartling et al 2014; Berggren and Hanson 2016; Inhestern et al 2016; Ellis et al 2017; Steiner et al 2017; Walczak et al 2018). Researchers recommended consensus work to identify relevant outcomes and choose measures which would be sensitive to changes in these.

The policy context

Policy responsibility for children's needs when a parent, sibling or someone else important is dying lies across end of life care and children's emotional and mental health. In both these fields there is an increasing drive for the routine use of patient-reported outcome measures (PROMS).

This study

This report responds to the practice, research and policy stimuli by

- reviewing areas of concern to families and practitioners about children's needs before a death in the family, and their attitudes to help from professional services
- scoping interventions and building consensus on the aims of support services in the UK
- reviewing current quantitative measures being used in evaluations in research and practice
- identifying key challenges to evaluating these interventions
- proposing a draft suite of self- and parent-reported measures to capture changes towards outcomes across services working with children facing the death of someone important.

Children's experiences and needs when someone in the family is seriously ill

The challenges children face when someone in the family is seriously ill differ by their relationship to the person who died and the changes the illness brings to the family roles, but there are similarities across experiences. These include changes in family routines, uncertainty, fear, caregiving responsibilities, lack of parental availability and attention, separation anxiety, loneliness, loss, economic pressures in the family (Spath et al 2007, Knecht et al 2015, Zegaczewski et al 2015, Walczak et al 2018, Eaton Russell et al 2018).

Both the literature on parental illness and that on sibling illness notes disruptions to children and young people's functioning, levels of distress, physical symptoms, quality of life and self-esteem, and debates the longstanding negative consequences (Prchal and Landolt 2010, Aldefefer et al 2010, Niemela et al 2010, Berggren et al 2016). The more positive aspects of these experiences, such as personal development, compassion and closer family relationships have received

much less attention (Joseph et al 2009, Prchal and Landolt 2010, Aldefefer et al 2010).

Things that help children include

- age-appropriate information about diagnosis and prognosis
- support in communicating with their parents and other family members
- peer support from others in a similar situation to reduce feelings of isolation and to feel 'normal'
- time out from the illness situation and support from friends
- practical assistance
- safe space to share feelings and worries and ask questions
- continuation of routines where possible
- tailored support to deal with feelings and distress and promote positive coping.

For parents, meeting these needs can be a huge challenge, whether they are ill themselves or caring for an ill partner or child.

Communication about the illness and prognosis is generally beneficial to children and young people, but is a significant challenge for families. Parents with life-limiting illness and their children want help from healthcare professionals in how to talk to, inform and support one another (Fearnley and Boland 2017, Kennedy and Lloyd-Williams 2009), as do parents and children when a sibling is seriously ill (Patterson et al 2011, Lovgren et al 2016).

Many parents and children face barriers to accessing support from outside the family. Apart from the challenges of acknowledging the situation and recognising that children might need support, barriers include finding the time while juggling medical care and appointments, getting to a service, and managing uncertainty as a disease progresses.

These process issues can shed light on ways of evaluating the outcomes of interventions, which this study considers.

Methods

Scoping review of interventions and methods

Electronic databases were searched to identify scoping reviews (n=12) that considered studies of interventions with children with a seriously ill member of the family. These were examined for details of the studies they included. Studies were retained if they focused on life-threatening illnesses and were clear about their aims. Forward searching from the scoping reviews added more recent intervention studies and protocols.

The aims of these interventions were identified. Those studies that described the use of quantitative, standardized measures to evaluate the intervention were included in a subsequent review of evaluation measures. Additional measures described in development or validation studies in this field were also added to the review.

Survey and focus groups with practitioners

Professionals supporting children before a death were recruited to an electronic survey through the membership bulletins of the Childhood Bereavement Network and Association of Bereavement Service Coordinators in Hospice and Palliative Care. The survey asked about current practice in this area, ways of assessing children's needs and evaluating the support and ideas for improving these, and questions on the wording of specific items in draft questionnaires for children, young people and their parents or other significant adults.

The same recruitment channels were used to recruit professionals to one of two focus groups. These included a presentation and discussion of survey findings and findings from a prior focus group on this topic. The focus group included prioritisation exercises on the aims of interventions, and detailed discussion on the content of draft questionnaires.

Findings

Seven of the 12 scoping reviews focused on interventions for children when a parent

is seriously ill (of these, only two specifically palliative care/incurable illness). Four studies considered interventions for children whose sibling was ill, and one included interventions when anyone in the family was seriously ill.

19 practitioners completed the online survey, and 23 attended a focus group. Hospice was the most common setting for these workers, followed by pre/post bereavement service. 58% survey respondents were counsellors, with other professional backgrounds including nursing, social work, management, dramatherapy and teaching.

The nature of interventions

Scoping review

Between them, the scoping reviews identified 44 relevant intervention studies (after duplicates were removed) and three more were found through forward searching. 60% focused on interventions for children facing the serious illness of a parent, and 34% on those with an ill sibling. 74% of interventions were for families affected by cancer. Other specific disease conditions included MND, HIV and MS.

40% of interventions focused on the whole family, 40% on the child, and 15% on an ill or well parent. 60% of interventions were offered in a group setting, and 38% to individual children, parents or families.

Most interventions supported children and families whatever the seriousness or stage of the illness: five were specifically aimed at families coping with advanced or terminal illness.

Practitioners' survey and focus groups

Generally, practitioners described more flexible and tailored interventions than those described in the published studies. Their work included support for the whole family, support directly for the child, support for parents and wider families, and support/liaison with other professionals

One to one if the pending bereavement is complex. Support and advice to parents. Workshop for parents. Family art project with children and person dying.

Social worker, hospice

The aims of interventions

Among the 47 interventions included in the scoping review, there were diverse aims. These were grouped broadly into seven areas. The most frequently mentioned aim is presented for each area.

- **Knowledge and attitudes towards illness** (36% aimed to increase the child's understanding of the illness).
- **Coping** (32% aimed to improve the child's coping).
- **Psychological functioning** (32% aimed to reduce or prevent emotional, behavioural or social problems).
- **Parenting, family functioning and relationships** (30% aimed to strengthen parenting or family functioning).
- **Communication, expression and social support** (26% aimed to improve family communication, 11% aimed to increase the child's connection to others in the same situation).
- **Quality of life and functioning** (15% aimed to increase the child's wellbeing, adjustment quality of life).
- **Self-concept** (11% aimed to increase the child's self-esteem).

These aims included proximal outcomes such as increasing the child's understanding of illness, as well as more distal outcomes that might result (eg reducing the child's emotional or behavioural problems. Many aims overlapped with or contributed to one another.

Practitioners prioritised aims. For children and young people, the most frequently endorsed aim was increasing the child's sense of who they can talk to in their support network. Other key aims were around improved communication, greater ability to recognise and manage feelings, and increasing understanding of what is happening. For parents, the most frequently endorsed aim was helping them to find a common clear language to explain the situation and changes.

Practitioners worked together to develop an outcome framework for this work.

Evaluating interventions

Across the intervention studies and practitioner survey and focus groups, 104 different standardized, quantitative measures that have been used to evaluate this work were identified. Of the 86 measures used in published studies, 77% (n=66) had been used in only one study.

49% (n=51) were about a child or young person, 32% (n=33) were about an adult, and 13% (n=13) could be used with an adult or adolescent. 5% were about the whole family (n=5) and two were about the parent/child relationship.

Measures were categorised according to the areas of aims already identified

- 11% of measures captured **knowledge and attitudes towards illness**
- 2% of measures captured **coping**
- 32% measures looked at **psychological functioning**
- 21% measures looked at **parenting, family functioning and relationships**
- 10% considered **communication, expression and social support**
- 16% captured **quality of life and functioning**
- 8% considered **self-concept**.

Practitioners described the techniques they used to assess children's needs. They were at very different stages of evaluating the support they provided

We do not have an effective means of evaluating the support provided.

Counsellor, hospice

Feedback from families informally captured in an email, evaluation from young people receiving 1:1 support, STAR evaluation.

Manager, bereavement service

We use a theory of change model – from presenting issues, via desired outcomes through to impact. We use various collection methods and collect all data.

Manager, pre-bereavement service

Issues with assessment and evaluation

Not unexpectedly, the great variety in outcomes measures was one of the chief methodological weaknesses that the scoping and systematic reviews identified across the intervention studies they included. They recommend consensus work to agree outcomes as a first step to identifying appropriate measures.

Other weaknesses included small sample sizes, short follow up, diversity of types of interventions, lack of process outcomes, specificity of setting and lack of diversity among participants making it difficult to generalise results, underuse of control groups, under-reporting of response and attrition rates, and lack of cost information.

Practitioners also identified a range of difficulties with evaluation. These focused more on the practical and philosophical challenges. Some difficulties were generic issues around evaluation, including time constraints, anxiety about reducing families to 'tickboxes', wanting child-friendly formats, and raising issues about the trade-offs between a comprehensive assessment measure and a sensitive outcome measure.

They also discussed challenges that were specific to the context of evaluating this type of support. The unpredictability of the illness progression requires flexible, tailored support which is harder to evaluate than a defined programme.

Goals based measures can be difficult when children's main hope is for the person not to die. It is hard to measure what you don't know – so capturing children's understanding of the situation is tricky.

Children and young people will be in different circumstances and 'states of knowing' when they first have contact with a pre-bereavement service. The outcome measure must be sensitive to this, not in itself giving children implicit news that has not yet been shared with them.

The biggest difficulty is around accounting for the challenge of the death that is to come.

'We need to take into account the grief and loss that will be experienced during our work together.'

Dramatherapist, palliative care service

Children will feel worse as time goes on – so any evaluation has to rate their understanding and source of support, and not use anxiety or depression illness approaches.

Counsellor, palliative care service

Focus group participants worked together on a series of draft questionnaires (Serious Illness in the Family Service Questionnaires SIFSQs) that capture changes towards the outcomes identified in this study, and which seek to overcome the identified evaluation challenges.

Recommendations

- Services should select outcome measures that are appropriate to their context and aims.
- Services should introduce their baseline/assessment measures as early as possible without disrupting the relationship practitioners are building.
- Services should consider when to do their post-intervention measurement to avoid coinciding with the death.
- Services should collect qualitative as well as quantitative data.
- The sector should work together to validate the Serious Illness in the Family Service Questionnaires (SIFSQs).
- Evaluation studies of pre-bereavement support for children should include process evaluations and careful reporting of refusal and attrition rates and reasons.
- CBN should seek funding for an online platform for the SIFSQs.
- CBN should approach collaborations working on palliative care outcomes and children's mental health outcomes to introduce the CBSQs and SIFSQs.
- CBN should work with funders to help them understand the challenges and possibilities of evaluating this type of support.

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