



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

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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.

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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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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, Aldefer 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, Aldefer 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.

Introduction

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).

Providing support

Over the last three decades, a range of services has developed across the UK to respond to bereaved children's experiences and needs (Penny 2011; Rolls and Payne 2003, 2004). Typically, these offer a range of 1:1 and group support for children and those caring for them, and support, training and resources for secondary users such as teachers, GPs and others working with children. 85% of these services are located in the voluntary sector, and 14% are dedicated childhood bereavement services while 86% are offered as part of a host organisation (hospices being the largest category) (Rolls and Payne 2003). Many of these services are members of the UK-wide Childhood Bereavement Network (CBN).

The landscape of support services for children before a death (pre-bereavement services) has not been studied in such detail. In 2003, 64% services working with bereaved children also offered support before a death (Rolls and Payne, 2003). From information given when services join CBN, it is known that many hospices and palliative care teams, as well as an increasing number of community-based child bereavement and other services, do support children where this is possible (Macpherson et al 2008a, 2008b; Chowns 2005, Hope Support Services). Additionally, there is a growing range of resources for children and young people including (Childhood Bereavement Network 2011), parents and carers (Macmillan Cancer Support and Winston's Wish 2015), and professionals (Fearnley 2012).

As with post-bereavement support (Penny 2011), this provision was stimulated by professional experience, particularly from the hospice movement's experience in working with dying patients (adults and children) and their families; pioneer services and an increasing demand for support from families themselves. Service development was also influenced by an expansion in research knowledge about children's and parents' experiences and needs when someone in the family is expected to die; and changing ideas about children, childhood, family life and bereavement.

Evaluating support

There are three aspects to an increasing drive to improve the evaluations of this form of support: practice, research and policy.

The practice context

After a death

However people engage with a service for bereaved children, they have an interest in whether it 'works'.

A parent or carer might want to know whether the service will be able to help their child manage the anxiety of separation during a school day. A worker in the service may want to know if it is making a lasting change to the families who express gratitude for the intervention. A young person might want to know if it has helped others find ways of coping with their overwhelming feelings.

Rolls and Penny (2011) p43

Funders and commissioners are also interested in the outcomes of a service, and this reflects a wider trend of a growing focus on the changes that a service brings about rather than the things it does (outcomes rather than activities) (Ellis 2009, Hoggarth and Comfort 2010).

A mapping of evaluation practices and challenges in UK child bereavement services found that services were struggling with the burden of demand for evaluation information from a range of users of evaluations. The most common forms of evaluation were post-intervention user satisfaction surveys of core interventions using self-completion questionnaires. However, collection of basic data was limited and patchy, and evaluations of outcomes and organisational processes were less common (Rolls and Penny 2011).

Rolls (2011) identified key challenges of evaluating this field.

- **The complexity of the context:** what is the nature of child bereavement and what outcomes should we value? What is the purpose of services? Whose voice matters? How do we account for the flexibility of tailored, non-manualised support, which children access at different times?
- **Evaluation as an activity:** what evidence is valued by whom? How can we control for a complex social process? Should we try and do this at all?
- **Concerns of services:** do inappropriate measures risk pathologising children's normal grief? Is benchmarking helpful in this context? Would evaluations be used as a justification for cuts in funding rather than a spur to improvement? Who will bear the resource burden of this activity?

In response to these challenges, Rolls (2007) recommended that the sector collaborate to strengthen current evaluation practice and develop a common-core routine evaluation package that could be used across all services, comprising a basic data set, a user satisfaction questionnaire and a childhood bereavement-focused clinical outcomes measure.

In the intervening decade, CBN has worked with stakeholders including bereaved children and young people, parents and carers, practitioners, managers, funders and commissioners of child bereavement services to develop these tools. Following piloting, they are now in use in around 25-30 services across the UK, and the outcome measure is currently being validated through an Economic and Social Research Council (ESRC) funded study.

Before a death

Throughout the project to develop an evaluation package for bereavement services, those CBN members who also support children before a death have asked if the package could

be adapted to evaluate this element of their work. This was too complex a project to do all at once, but has been recommended consistently by CBN members as the next priority for CBN.

Returning to the original impetus for evaluation as a way of answering the question 'does this service work?', it could be argued that this question is even more urgent when evaluating pre-bereavement than post-bereavement services. Before a death, families have limited time together, and it is vital that this time is not wasted on services or interventions that are not helpful.

The research context

In parallel to this practice impetus, researchers have also been calling for stronger evaluations of support for children before a death. While published qualitative evaluations are consistently positive, recent literature reviews have found quantitative evidence on services' effectiveness to be 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).

The literature on services or interventions support children before someone important to them dies is rather divided, with studies and systematic/scoping reviews tending to focus either on children when a parent is ill, or when a sibling is ill, or when children have caring responsibilities. Only a small number of intervention studies (Bedway and Smith 1996, Naudi et al 2002) and reviews (Spath et al 2007) consider the shared needs of children whether it is a parent or sibling that is ill. This may be because psychosocial support for close family members tends to be organised through the health services for the patient, which would generally treat ill adults (parents) and children (siblings) separately.

Research on young carers (Joseph et al 2009) Pakenham and Cox 2015, Chikradze et al 2017), and services organised for them, as well as community based child bereavement organisations (Rolls and Payne 2003) are more likely to consider and address the needs of these children and young people together.

Despite the divides between these literatures, their conclusions about ways in which evaluations could be strengthened are similar. For children whose parent has cancer, reviewers recommended consensus work to agree the intended outcomes of interventions as a necessary first step to identifying appropriate measures to capture changes towards those outcomes (Ellis et al 2017, Walczak et al 2018). Niemela et al (2010) argued that this consensus should be based on clinical experience as well as research evidence. In relation to children whose sibling is ill, Hartling (2014) also recommends careful consideration of what interventions are intended to effect and hence what the most appropriate outcome measures would be.

The policy context

The third impetus for improved evaluation of pre-bereavement support for children comes from the policy agenda. Across the four nations of the UK, support for children facing the death of a parent, sibling or someone else close lies across policy responsibilities for end of life care and for children's emotional health (Penny and Stubbs 2015).

End of life care

In England, the government's response to the *Review of Choice at the End of Life* in July 2016 called on commissioners to consider how they can structure services that offer accessible, high quality bereavement services for children and their families (Department of Health 2016). It also called for further funding for research into palliative and end of life care, focusing on the priorities identified by the James Lind Alliance, one of which to understand the best ways to support children when someone close to them is dying.

The Ambitions for Palliative and End of Life Care state that

Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people.

(National Partnership for Palliative and End of Life Care 2015)

NHS England is working on a suite of metrics to capture patient and family/carer experience at the end of life (National End of Life Care Programme Board, 2017). While it is unlikely that this would include a measure of the experience of children in the family, it does build the case for more insights into the experience of families and carers at the end of life, including the outcomes of interventions to support them.

Emotional and mental health

The 2015 report *Future in Mind* emphasizes the importance of emotional and mental health services for children and young people that include 'evidence based treatments that meet [young people's] goals and address their priorities'. The 2017 Green Paper on Children and Young People's Mental Health identifies that children and young people who have been bereaved are a group who may need particular attention from the proposed Mental Health Support Teams. The paper also outlines plans to incentivise schools to appoint a Designated Lead for Mental Health, whose responsibilities will include overseeing the outcomes of interventions on children and young people's well-being.

This report

This report responds to the practice, research and policy stimuli outlined above, addressing a significant gap 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 in different circumstances

The report draws on the sometimes separate literatures on children with an ill parent, children with an ill sibling and young carers, analysing these together and looking for commonalities in experiences where possible. Pragmatically, many services in the UK support children regardless of who in the family is dying, so any evaluation measures or methods proposed need to work across different circumstances.

Terminology

The language around care of people with terminal illness – and of people important to them – is complex and contested. 'Dying' tends to imply imminent death, and many alternative terms are used to describe types and stages of illness, including 'life-limiting', 'advanced', 'serious', 'incurable', 'terminal', 'life-threatening', 'end-stage'. ACT usefully categorised children's life-limiting and life-threatening conditions into four broad groups (2009)

- Life-threatening conditions for which curative treatment may be feasible but can fail (eg cancer, irreversible organ failures of heart, liver, kidney).

- Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities (eg cystic fibrosis, Duchenne muscular dystrophy).
- Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (eg Batten disease, mucopolysaccharidoses).
- Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (eg severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury).

Terms for the care provided at this stage include 'palliative', 'supportive' and 'end-of-life'. Support for the family and others likely to be impacted by the death might be described as 'pre-bereavement support' or 'support when someone is expected to die' or 'support when someone is seriously ill'.

Two explanations for this variety and complexity of language are the general uncomfortableness in society towards talking about death, and the uncertainty around death. The later stages of disease may last for many years, and even when death is close, it is notoriously difficult to diagnose.

In essence, the type of support described in this report is that which is intended to help children when someone close to them is expected to die. Depending on the type of condition that the person has and the trajectory it follows, this work may start at the point of diagnosis. This work might start at the point of diagnosis, pick up pace when no further curative treatment is possible or when complications emerge, and intensify when death is closer.

Throughout this report, 'children' is taken to mean 'children and young people', except where children are specifically contrasted with older young people.

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

The literatures on children's experiences when a parent or sibling is seriously ill have tended to develop separately. In both cases, there is more research on the needs of children or siblings dealing with the onset and progress of life-threatening illnesses (particularly cancer) in their family than on the implications of living with a chronic life-limiting illness, and this is reflected in the palliative and end of life care literature (Gaab et al 2013, Verberne et al 2017).

The challenges children face differ significantly by their relationship to the person who is ill and the changes the illness brings to the family roles and attachments (Pakenham and Cox 2015), but there are also similarities across experiences. These include changes in family routines, uncertainty, fear, responsibilities including caregiving, 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, Aldefer 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 receive much less attention (Joseph et al 2009, Prchal and Landolt 2010, Aldefer et al 2010).

Despite these literatures developing in parallel, there are considerable overlaps in conclusions about the needs of children when a parent or sibling is seriously ill. These include

- age-appropriate information about their parent's cancer (Ellis et al 2017, Walczak et al 2018) including its prognosis (Walczak et al 2018), or sibling's chronic health condition (Inclendon et al 2015) or cancer (Patterson et al 2013)
- support in communicating with their parents and other family members so that their needs and feelings are understood (Patterson et al 2013, Inclendon et al 2015, Ellis et al 2017)
- peer support from others in a similar situation to reduce feelings of isolation and to feel 'normal' (Patterson et al 2013, Inclendon et al 2015, Zegaczewski et al 2015, Ellis et al 2017, Walczak et al 2018)
- time out from the illness situation and support from friends (Patterson et al 2013, Walczak et al 2018)
- practical assistance (Patterson et al 2013, Walczak et al 2018)
- safe space to share feelings (Ellis et al 2017) and worries and ask questions (Berggren and Hanson 2016)
- continuation of routines where possible (Buchbinder et al 2009, Inclendon et al 2015)
- tailored support to deal with feelings and distress and promote positive coping (Patterson et al 2013, Inclendon et al 2015, Ellis et al 2017, Walczak et al 2018)
- specialised support and continued connections when the illness progresses or if their the family member dies (Ellis et al 2017).

Meeting these needs is a huge challenge to parents, whether they are ill themselves or caring for an ill partner or an ill child.

When a parent is ill

Ill parents have to meet their children's needs while coming to terms with the fact that they are dying. Worry for their children – especially the emotional impact their death will have - is their most troubling concern at diagnosis of advanced illness (Park et al 2017).

These concurrent challenges leave cancer patients with children more anxious and depressed than those without (Park et al 2016), and influence their treatment decisions. This can include the desperately difficult competing priorities (Check et al 2017) of lengthening the time they have with their children (by choosing aggressive treatment over palliative care (Yellen and Cella 1995, Nilsson et al 2008, Park et al 2017)), versus preserving their physical capacity to parent their children (through choosing less aggressive treatments). Parents with cancer with dependent children are less likely to engage in advance care planning (Nilsson et al 2009) and their treatment choices have implications for how long palliative care services have to help them prepare their children for death

Well parents are faced with often painful dilemmas about how to prioritize potentially competing and conflicting priorities of their dying partner, themselves and their children (Macpherson 2005). They often express worries that their own distress will make it difficult for them to meet their children's needs, and they lose confidence in their own parenting competence (Siegel et al 1990). Caring for a dying partner is hard enough, but caring for children at the same time and meeting their needs increases the risk of clinical levels of depression and anxiety (Nilsson et al 2009). The well parent and their partner's needs and experiences are closely entwined at the end of life: widowed fathers report low levels of peacefulness among their wives at the end of life, and these low levels are themselves associated with fathers' higher risk of depression (Park et al 2016). The well parent's capacity to support their child before and after the death is a critical factor in how the child adjusts (Christ et al 2006, Worden, 1996).

Communication

One of the greatest challenges for parents when one of them is terminally ill is how to talk to the children about illness and prognosis. Even in families with generally open communication style, and where children have been told about the illness, this may not extend to being told about the possibility of probability of death (Siegel et al 1996). Over a third of widowed fathers say their wives had not been able to say goodbye to their children before they died (Park et al 2015). Almost half of young people recalling their experiences of the death of a parent when they were 13-16 years old say they hadn't realised the death was imminent until a couple of hours beforehand (Bylund-Grenklo et al 2015). But even before the death is imminent, children and young people want to know what is going on so that they can be prepared for the future and feel involved in the family (Kennedy and Lloyd-Williams 2009), and advise others in the same circumstances to talk to someone about the illness (Thastum et al 2008).

Reasons for not discussing the illness and death include children and parent's wish to protect one another and uncertainty about how to go about opening the conversation, parents' feelings of guilt, fear and grief and in some cases unawareness of their children's distress (Kennedy and Lloyd-Williams 2009)

However, most children report being aware of cancer, for example, as a life-threatening illness (Forrest et al 2006, Long et al 2015) and are likely to fear the possibility that their parent will die. The inability to voice and discuss this fear may account for the increased anxiety among children and young people who have not been told (Beale et al 2004), although the relationship between disclosure and children's outcomes is complex (Sheehan et al 2014).

Families show different patterns of disclosure about a parent's likely death along a continuum influenced by the dying parent's wishes (Macpherson et al 2005). While 'measured telling' seems to be the model for healthy disclosure of illness and imminent death, parents and young people in families using 'skirted telling' or 'matter of fact telling' also seem satisfied

with these approaches. It is families where the telling is inconsistent that might need particular help (Sheehan et al 2014). But telling is not without cost, with greater communication about the illness associated with more anxiety (but not depression) in the ill parent (Hailey et al 2018), underlining the need for healthcare professionals to support families with this difficult task.

Support from healthcare professionals

Most parents with life-limiting illness want support from healthcare professionals about how to talk with and support their children following diagnosis, but often do not get it (Fearnley and Boland 2017). Children also identify healthcare professionals as a useful source of information and support, particularly when they don't want to upset their parents by talking with them or are unsure about how to open up conversations. However, they report difficulties in accessing professional help (Kennedy and Lloyd-Williams 2009). Teenagers who received no information from professionals when their parent died of cancer are more likely to mistrust the care that was provided (itself associated with greater depression) (Bylund-Grenklo et al 2013).

When a sibling is ill

When a child has a life-threatening or life-limiting illness, parents are frequently providing complex care while maintaining and reorganizing family routines and roles, all the while confronted with the devastating prospect of the death (Verberne et al 2017, Mooney-Doyle et al 2018).

Siblings of dying children are their playmates, companions and helpers, and the balance of these roles shifts as the disease progresses (Eaton Russell et al 2017). Parents describe the challenge of trying to meet their ill and well children's concurrent needs (Patterson et al 2004, Alderfer et al 2010, Mooney-Doyle et al 2018), and their conscious effort to set aside time for, and protect, their well children and maintain the family balance (Ray 2002, Verberne et al 2017). They find meeting their well children's needs emotional needs to be one of the hardest and most time-consuming aspects of dealing with childhood cancer (Svavarsdottir 2005). They report feeling guilty about not being more available to siblings, and worry about the effect this will have on them (Sidhu et al 2006).

Despite parents' best efforts, siblings' needs can be overlooked when a child is at the end of life. They report family reorganization and their parents being less available while their brother or sister is being treated for cancer, but many also describe how the family pulls together (Long et al 2015). Those whose sibling died of cancer are much more likely to be anxious several years later if they didn't get the social support they needed from family, friends and neighbours in the month before the death (Eilertson et al 2013).

Siblings report their ability to comfort their brother or sister as one of their biggest problems during the terminal phase (Freeman et al 2003). They benefit from inclusion and participation in the care of a sibling at the end of life (Lauer et al 1985, Giovanola 2005), and some want more help in making this happen (Lovgren et al 2016).

Communication

Information and communication can be a particular problem. Siblings of children with cancer fear the life-threatening aspect of the disease (Long et al 2015) and report that their greatest unmet needs are in dealing with their feelings about the possibility that their brother or sister might die (Patterson et al 2014). A lack of information about dying and preparation for the death are among children's greatest problems when their sibling is at the end of life (Freeman et al 2003, Nolbris and Hellstrom 2005). Efforts to protect siblings at this phase of the illness can mean that information is kept from them, leading to feelings of isolation, confusion about what is happening and a harder time coping with bereavement (Giovanola 2005, Gaab et al 2014). Limited information and poor communication with family, friends and healthcare staff about death are associated with siblings' unresolved grief (Wallin et al 2016).

Most siblings of children with a range of chronic conditions, whether or not they have already been bereaved, feel it is important to discuss the impending death because it increases their understanding and helps them prepare (Gaab et al 2014). This doesn't mean talking about the death all the time – they also need respite and normality.

Support from healthcare professionals

Healthcare professionals are an important potential source of information and support. However, some bereaved siblings report feeling unprepared by professionals, who didn't see them as people who need to be kept informed and included when their sibling was at the end of life (Nolbris and Hellstrom 2005).

They express a need for access to support services and professional help: someone to talk to, support for daily life, and support groups and other activities (Patterson et al 2011, Lovgren et al 2016) including opportunities to meet others in the same situation (Nolbris and Hellstrom 2005). As well as support, some siblings recommend that healthcare professionals provide siblings with information about the disease, treatment, progression and prognosis. Some want parents to be given information about talking to, helping and involving siblings (Lovgren et al 2016).

Accessing support: barriers and facilitators

Despite parents and children recognising the support that healthcare professionals can bring, there are significant barriers to families taking up or sticking with this support, even where it exists. Inhestern et al (2016) reviewed the barriers to children's participation in nineteen different psychosocial interventions when a parent has cancer. These included:

- **physical difficulties for families** including finding the time, travelling to where the intervention was happening, whether they had qualifying health insurance (in the case of some US interventions)
- **emotional barriers** including parents not recognising their child's need for support, trying to avoid emotional overload, fear of stigma,
- **disease characteristics** including the symptoms and progress of the disease, and the phase of treatment. For example, Christ (1991) reported that parent patients and their families had difficulty in accepting the failure of treatment
- poor collaboration between clinics and institutions.

Things that made it easier for families to participate included good information about the support and an easy way of getting in touch, a flexible structure (such as including separated and divorced partners, and new step-parents), and practical offers such as childcare or meals. Accessible premises and staff with good communication skills and cultural sensitivity also helped. Parents needed to have accepted their disease and situation for themselves before seeking support for their children, and they needed to perceive a need (such as having noticed a change in their child's behaviour).

Many of these barriers and facilitators were mentioned by those reporting interventions for siblings, too. These included difficulties with transport or other logistics (Dolgin 1997, Gursky 2007); one group minimised these by offering the intervention as a residential camp rather than a series of weekly meetings (Sidhu et al 2006). Ahead of an intervention, clinical staff responsible for recruiting families can fear it will cause distress among siblings who are coping by using distraction or denial, and worry that parents will be left to pick up the pieces after the intervention is finished.

Regular feedback to parents about how their child is doing (within the parameters of confidentiality) can help with retaining families (Christ et al 1991, Dolgin 1997).

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

Methods

Scoping review of interventions and measures

Electronic databases (Pubmed, Medline, Web of science, ASSIA, ProQuest) were searched in November 2017 to January 2018 to identify relevant systematic and scoping reviews of studies evaluating supportive interventions for children when a parent or sibling is seriously ill. Search terms included (child*, young person, young people, youth, adolescen*) (sibling, brother, sister, parent*, mother*, father*) (illness AND advanced, terminal, life-limiting, life-threatening, palliative, cancer, serious, incurable) (review, scoping, systematic, overview).

Searches returned a very large number of studies exploring the needs of parents whose child was seriously ill (without reference to healthy siblings) and these were excluded from the analysis. Scoping reviews that included studies of interventions with children with a seriously ill member of the family were retained.

Review of aims

These scoping and systematic reviews were examined for details of the studies they included. Studies that focused on serious but not life-threatening illness were excluded, as were those in which the family member had recovered and not relapsed. Studies that included children whose family member had a life-threatening but early stage illness (eg stage I-III cancer) were included, as the known uncertainties that children face and their awareness of cancer as a life-threatening illness (Forrest et al 2006, Long et al 2015) make early interventions relevant to this analysis. Studies that described children's needs in these circumstances were excluded if they did not describe an intervention, or make its aims clear.

Forward searching from the scoping and systematic reviews added more recent intervention studies and protocols.

Review of evaluation measures

The included studies that described the use of quantitative, standardized measures to evaluate the intervention were included in a subsequent review of evaluation measures. Studies were excluded if they only measured parents' reports of their own outcomes (no outcomes for the children, whether self- or parent-reported). Measures which were specifically about the physical symptoms of the ill person were excluded, but those which were about their quality of life/functioning were included, as these may be the target of programmes intended to benefit children in the family.

Additional measures described in development or validation studies were also added to this review.

Review of issues with evaluations

Weaknesses in evaluation study design that were noted by the systematic and scoping studies were coded.

Survey of professionals

A survey was developed to gather the views of those delivering pre-bereavement support to children and young people. Members of the Childhood Bereavement Network (CBN) were invited to participate, via the regular member's bulletin and Twitter, supplemented by dissemination to member of the Association of Bereavement Service Coordinators in Hospices and Palliative Care (ABSCO) via Hospice UK.

The survey included questions about participants' current practice in supporting children and young people facing bereavement, and how this related to the support they offered after a death, if relevant. It asked participants about their current methods for assessing children's

needs and evaluating the support they offered, and their views about how these could be improved. It included specific questions on the wording of draft questionnaires for children and young people and the significant adults in their lives.

Standardized questionnaires which participants described using were added to the review of measures described above.

Focus groups with professionals

Professionals working with children before a death were invited to attend one of two focus groups in January 2018 via regular update emails to CBN and ABSCO members. Focus groups lasted a full day and included a presentation and discussion of survey findings, prioritisation of the aims of intervention and detailed discussion of the content of draft questionnaires. Notes were taken during the meeting.

Notes from a meeting of pre-bereavement professionals held by the Childhood Bereavement Network in December 2014 were examined and re-analysed. Participants had been recruited to this focus group through the CBN members' bulletin.

Results

Overall results are presented first, and subsequent chapters look in detail at the nature of interventions, the aims of interventions, quantitative measures being used, and issues with evaluation.

Scoping review

Searches yielded 12 relevant scoping and systematic reviews, presented in table 1 below. Seven were concerned with children when a parent was seriously ill, of which five were specific to cancer (Niemela et al, 2010; Inhestern et al 2016; Ellis et al 2017; Steiner et al 2017, Walczak et al (2018). Of these, only Steiner et al (2017) focused on incurable cancer. One was about parents with serious physical illness (Berggren and Hanson 2016) one focused on children with a parent receiving palliative care (Kuhne et al 2012).

Four studies looked at interventions for children with an ill sibling: two for siblings of children with cancer (Prchal and Landolt 2014; Zegaczewski et al 2016) and two for siblings of children with chronic illness or disability (Hartling et al 2014; Incedon et al 2015). The remaining study reviewed interventions for children with an acutely ill family member (Spath et al 2007).

Table 1: Systematic and scoping reviews of children when a close relative is seriously ill

Target group for interventions Author (year)*	Type of interventions & studies	Number of interventions (number of studies)
Children facing a family member's acute illness Spath (2007)	Quantitative studies of educational, psychological and supportive interventions	6
Siblings of pediatric cancer patients Prchal and Landolt (2009)	Interventions with standardized and validated outcome measures on psychological adjustment and/or quality of life; satisfaction with intervention; or medical knowledge	14 (22)
Families with a parent with cancer Niemela et al (2010)	Structured family or peer group interventions directly targeting children	11
Minor children of palliative patients Kuhne et al (2012)	Psychosocial family interventions	5 (24)
Siblings of children with chronic illness or disability Hartling et al (2014)	Programmes, support services or therapy reporting at least one quantitative outcome for well siblings	14
Siblings of children with chronic illness Incedon et al (2015)	Quantitative and qualitative studies identifying modifiable factors at child, parent or family level	7
Families with parental cancer Inhestern et al (2016)	Structured psychosocial support	19 (36)
Children who have a parent with a serious physical illness Berggren and Hanson (2016)	Support interventions	9 (12)

Healthy siblings of children with cancer Zegaczewski et al (2016)	Quantitative studies relating to well siblings' psychosocial adjustment, with a minimum sample size of 30	5
Children facing a parent's cancer diagnosis Ellis et al (2017)	Studies of children's psychosocial needs and evaluations of existing interventions	12
Parents with incurable cancer Steiner et al (2017)	Psychosocial interventions with outcomes for parents	4
Adolescents and young adults with a parent with cancer Walczak et al (2018)	Quantitative and qualitative studies of psychosocial impact, including intervention studies	5 (6)

* Studies are presented in order of publication date

Between them, these reviews identified 156 relevant studies on 111 relevant interventions. Once duplicates were removed, 55 studies were left, describing 44 relevant interventions. Forward searching revealed four further studies describing three further interventions: two protocols (Hauken et al 2015; Stafford et al 2017), one further trial of an already included intervention (Lewis et al 2017), and one post-intervention evaluation (Varathakeyan et al 2018).

Survey and focus groups of practitioners

19 practitioners completed the online survey, and 23 attended a focus group. Their characteristics are presented in table 2 below.

Table 2: Participants in practitioner survey (n=19) and focus groups (n=23)

Characteristic	Survey		Focus group	
	N	%	N	%
Organisational setting				
Hospice	11	57.9	8	34.8
Pre/post bereavement service	4	21.1	6	26.1
Community palliative care service	2	10.5	1	4.3
Hospital palliative care service	1	5.3		
NHS CAMHS	1	5.3	2	8.7
Other			4	17.4
Professional background				
Counsellor	11	57.9		
Nurse	2	10.5		
Social worker	2	10.5		
Manager	2	10.5		
Dramatherapist	1	5.3		
Teacher	1	5.3		
Total	19	100.0	23	100.0

The nature of interventions

This chapter outlines the type of interventions that were described in the studies included in the scoping review and by survey and focus group participants.

Scoping review

A summary of the 47 interventions included in the scoping review is presented in the table below, and further details on all the studies are show in appendix 2.

Table 3: Characteristics of the included interventions

Characteristics of interventions (n=47)	N	%
<i>Circumstances in which the intervention was offered</i>		
Ill parent	28	59.6
Ill sibling	16	34.0
Ill parent or sibling	1	2.1
Ill parent, grandparent or close relative	2	4.3
<i>Illness type</i>		
Cancer	35	74.4
Cancer or MND	1	2.0
Chronic illness, developmental disability or special needs	4	8.5
HIV	4	8.5
Hospitalization	2	4.3
Multiple sclerosis	1	2.1
<i>Focus of the intervention</i>		
Whole family	19	40.4
Parent (ill or well)	7	14.9
Child	19	40.4
Child and ill sibling	2	4.3
<i>Families/parents/children seen individually or in groups with other families/parents/children</i>		
Group	28	60.0
Individual	18	38.0
Mixed	1	2.0

The majority of interventions supported children and families whatever the seriousness or stage of the illness. Five studies were specifically aimed at families where the ill person had advanced illness or was terminally ill (Bugge et al 2008, 2009; Christ et al 2005; Greening 1992; Kissane et al 2006, 2016; Naudi 2002).

Three interventions excluded families where the parent had stage IV or metastasised cancer (Davey et al 2012, 2013; John et al 2010, 2013; Lewis et al 2015). One only included those having curative treatment with a view to long-term survival (Stafford et al 2017); one excluded families where the ill sibling was at end stage (Lobato and Kao 2002) and one excluded families where the sibling was not expected to die within 18 months (Williams et al 2003).

Interventions varied in length from one three-hour session to 22 weekly sessions. Most were delivered face to face but one trial (Lewis et al 2017) and one protocol (Stafford et al 2017) reported on a telephone intervention, in both cases for parents with early stage cancer.

Practitioners' survey and focus groups

Practitioners completing the survey were asked about the circumstances in which they support children and young people. The majority were supporting children when a close family member was dying. Slightly more services were supporting children after a death than before.

Table 5: Circumstances in which participants' services (n=19) support children and young people

Circumstances	N	%
When a parent is dying	17	89.5
When a parent has died	18	94.7
When a sibling is dying	13	68.4
When a sibling has died	15	79.0
When someone else close is dying	17	89.5
When someone else close has died	17	89.5

Pre- and post-bereavement support

Those survey respondents who worked in organisations supporting children both before and after a death were asked how these two services linked together.

The majority of services (n=10) always used the same person to support a child before and after the death, while one service always used a different person.

Five services had a mixed approach, based on the preferences of the family and who was available to support the child.

Depending on different things although we recognise it can be most helpful if there is continuity.

Counsellor, bereavement service

We do swap volunteers as things mentioned before a death may change afterwards and the child is in a very different place after the death and therefore may not feel as comfortable with the same volunteer. Although if the same volunteer is requested then we will oblige.

Counsellor, hospice

Same person if the work is continuous. If there is a break, it's possible it may be someone else.

Counsellor, hospice

What organisations offer

Generally, respondents were offering a range of services tailored to the family's needs:

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

Supportive visits to hospital. Advice to parents about how best to communicate with children/young people. Liaison with schools and other support. Direct work with children pre-bereavement.

Social worker, hospital palliative care service

A variety of resources are offered and parents coached to use them

Counsellor, NHS hospice/palliative care service

Respondents described the support they offer in their own words. The majority of respondents mentioned providing 1:1 support for children and young people, and most described some form of support to the adults around the child, including parents, the wider family and schools. Some were liaising with other key professionals.

Table 6: The nature of support offered by survey respondents (n=19)

Type of support	N	%
Support for the whole family		
Assessment meeting or visit	2	10.5
Family meetings and sessions (including art projects)	5	26.3
Holidays	1	5.3
Support directly for the child		
1: 1 support for the child (sometimes only in complex or occasional circumstances), including counselling, play or drama therapy	17	89.5
Peer or group support	3	15.8
Sibling group support	1	5.3
Supportive visit to hospital		
Support for parents and families		
Support and advice to parents/families (in person and phone)	6	31.6
Resources (including coaching in their use)	3	15.8
Workshops for parents	1	5.3
Support and liaison with other professionals		
Schools	5	26.3
Other agencies	2	10.5
Medical professionals	1	5.3
Training	1	5.3

The aims of interventions

The interventions described in the studies included in the scoping review and by practitioners were aiming to bring about a range of changes for children and their families.

Scoping review

Among the 47 interventions included in the scoping review, there were diverse aims, presented in table 4 below. While some studies included aims targeting the well or ill parent, these were theorised to have an impact on the children in the family.

Table 4: Frequency of aims described in intervention studies (n=47)

The aims of interventions	N	%
Knowledge and attitudes towards illness		
Increase child's understanding of illness	17	36.1
Improve child's feelings and attitudes to illness	3	6.4
Coping		
Improve child's coping	15	31.9
Psychological functioning		
Reduce or prevent child's emotional/behavioural/social problems	15	31.9
Reduce (well or ill) parent's psychological distress	4	8.5
Improve child's mood	3	6.4
Relieve stress	1	2.1
Parenting, family functioning and relationships		
Strengthen parenting/family functioning	14	29.8
Improve child's perception of parent	2	4.3
Improve parent's sense of parenting competence/efficacy	2	4.3
Help family plan for the future	2	4.3
Prevent children's 'dysfunctional parentification'	1	2.1
Respite to parents	1	2.1
Communication, expression and social support		
Improve family communication (general or unspecified)	12	25.5
Improve family communication (about illness & impact)	6	12.8
Enable child to share feelings/worries about illness & normalise	5	10.6
Increase social support for child	5	10.6
Increase child's sense of connectedness to others in same situation	5	10.6
Support anticipatory grief	2	4.3
Improve child's social competence	1	2.1
Quality of life and functioning		
Improve child's well-being/adjustment/quality of life	7	14.9
Support child to keep up with activities	1	2.1
Quality time for children	1	2.1
Self-concept		
Increase child's self-esteem	5	10.6

Aims have been grouped into seven broad areas of understanding the illness; coping; psychological functioning; parenting, family functioning and relationships; communication, expression and social support; quality of life and functioning; and self-concept. These overarching areas were difficult to define as many of the aims overlap and contribute to one another. For example increasing family communication is closely related to enabling the child to share their feelings or worries, increasing the child's understanding of the illness, and improving the child's perception of their parent.

These aims included proximal outcomes (such as increasing the child's understanding of illness, strengthening parenting, improving family communication about the illness), and also distal outcomes that might result (eg reducing the child's emotional or behavioural problems, increasing the child's quality of life, increasing the child's self-esteem).

Practitioners' focus groups

Notes from the initial focus group were used to generate a list of intended outcomes of this work, which practitioners at the subsequent focus groups prioritised.

For **children and young people themselves**, the most frequently endorsed outcome was increasing the child's sense of who they can talk to in their support network. The next most frequently endorsed items were around

- communication (increasing their sense of permission to talk and be honest, increasing the use of a common language to explain what is happening eg between home and school)
- the ability to recognise and express feelings
- increasing their understanding of what is going on (including being given appropriate information including through a stepped approach, and helping them recognise differences and changes).

Practitioners also prioritised children's right to be a child, have fun and participate in other activities. They mentioned reassurance in giving children hope about the future and the memories that would endure. As well as support in the family, participants mentioned the importance of children and young people's choices about how they wanted their school to support them.

For **parents and families**, practitioners prioritised similar outcomes that would ultimately impact on the children in the family. The most frequently mentioned were increasing families' capacity to find a common, clear language to explain to children what was happening at different stages of the illness, and increasing a shared recognition of their child's understanding, linked to their developmental stage. Participants also prioritised

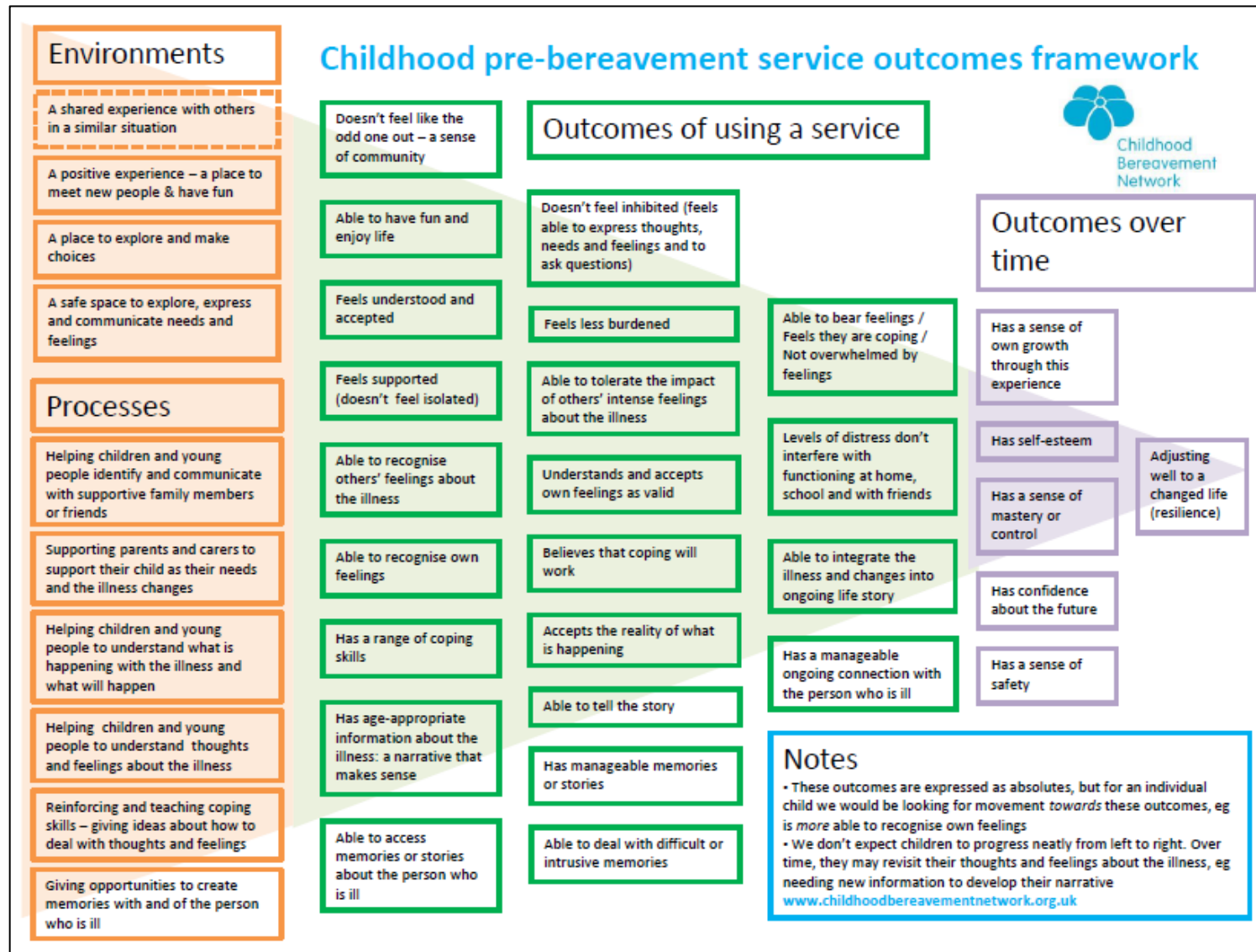
- increasing families' access to information and support
- increasing ill and well parents' confidence, belief in themselves and expertise in their own children
- giving parents hope and reassurance that their children will be ok
- increasing families' capacity to be open to feelings and to acknowledge one another's feelings
- reducing loneliness and isolation.

An outcomes framework

Practitioners worked together to incorporate these outcomes into a revised version of the CBN Outcomes Framework (Childhood Bereavement Network, 2013), shown in figure 1. The original Framework was developed to describe the environments, processes (things that happen) and outcomes (things that change) as a result of the work of support services for children after a death. The main adaptations which practitioners made to make this suitable for pre-bereavement work were

- replacing the word 'death' with 'illness'
- replacing 'grief' with '(intense) thoughts and feelings about the illness'
- replacing 'what happened' with 'what is happening with the illness and what will happen'
- supplementing 'supporting parents and carers to support their children' with 'as their needs and the illness changes'
- replacing 'feels relieved' with 'feels less burdened'
- replacing 'giving opportunities to remember the person who died' with 'giving opportunities to create memories with and of the person who is ill'.

Figure 1: Outcomes framework for pre-bereavement services for children



Evaluating interventions

This chapter describes how practitioners and researchers currently evaluate their interventions to support children and young people when someone in the family is seriously ill.

Scoping review: evaluation methods in intervention studies

47 interventions were included in the review of interventions, described in 59 studies, and these are summarised in appendix 1. Studies were published between 1984 and 2018.

Three interventions were not described in evaluation studies: the Art Therapy Programme for Children (Weiss et al 2005), Children of Somatically Ill Parents (COSIP) Finland (Schmitt et al 2007) and the School-based support group (Call, 1990). Eleven interventions used qualitative methods to evaluate the support available, and a summary of their findings is in Appendix 1. Generally, satisfaction with support was high. Two studies used quantitative measures but only after the intervention (Heiney and Lesesne 1996, Paschen et al 2007).

This left a total of 31 interventions which had been evaluated using standardized quantitative measures before and after the intervention, and in some cases at follow up. The longest follow up was six years after the intervention (Rotherham-Borus et al 2004).

Quantitative outcome measures

The studies describing these 31 evaluations were explored to identify the measures that had been used (or would be used, in the case of the two protocols). Additional measures were identified through searches for relevant validation studies and reviews of measures, including those for young carers (Grosse Schlarman et al 2008, Joseph et al 2009, Cox and Pakenham 2014), and for children with a sibling (Patterson et al 2011, 2014) or parent (Patterson et al 2013) with cancer. Finally, measures which survey and focus group participants mentioned were included.

This yielded a total of 104 different measures, which are presented in appendix 2. These included 86 measures that were used in one or more of the included intervention studies (including the two protocols); 11 that were described in validation or measure development studies; and 7 that were mentioned by survey respondents only.

Of the 86 measures used in studies, 77% (n=66) had been used in only one study.

Who the measures are about

51 (49.0%) of the measures were about **children or adolescents**, of which 13 were specifically about children and young people who are young carers or have an ill parent or sibling. 33 (31.7%) measures were about **adults**, of which 17 were specifically about parents, and 9 of which were specifically about adults or parents who are ill. 3 were about parents who are well and whose partner is ill. 13 (12.5%) measures could be used with **both adults or children/young people**. Five measures (4.8%) were about the **whole family**, and two were about the relationship between a parent and child.

Who completes the measures

81 measures were self-reported by the person who the measure was about. Of these, 68 measures were designed for completion by the child or young person (18 of these could also be completed by adults).

9 measures were about the child, reported by the parent. 2 measures were about the parent, reported by the child. 13 measures were reported by both the parent and the child.

Many self-report measures for children specified a minimum age for which the measure had been validated or used successfully. Of these, the youngest age was four (the young children's version of the KINDL). The modal minimum age specified was seven, specified by 10 measures.

What the measures are measuring

The seven broad areas of intervention aims outlined in the previous chapter have been used to categorise the measures, which are presented in the table below. Details of the individual measures are presented in Appendix 2.

11 measures looked at an aspect of the child's **knowledge and attitudes towards illness**. This included measures of feelings about the illness, attitudes to it, knowledge about it, benefit finding in relation to it, and needs related to it. As would be expected with such subjective concepts, these were all about the child, and were all self-reported

2 measures captured **coping**. One was a self-report measure of children's coping when a parent has MS and the other was a self-report measure of coping for parents with HIV.

33 measures captured **psychological functioning**. This included measures of anxiety, depression, grief, internalising/externalising problems, mood, post-traumatic stress, problematic behaviour, distress, physical symptoms and general mental health, as well as positive feelings. 17 of these measures were about the child, 9 were about the adult/parent and 7 could be used in relation to either the child or the parent. Of the 24 measures which could be used about children and young people, 18 were self-reported, three were reported by the parent, and three could be reported by both the parent and the child.

A further 22 measures captured an aspect of **parenting, family functioning or relationships**. These included functioning of the family and of the ill person, the child's caregiving activities and the impact of caregiving, family routines, parenting style, parenting concerns and parenting self-efficacy, social functioning, relationships. One measure screened for the family's psychosocial risk. Of these measures, 13 were generic measures, while 9 captured an aspect of families' lives in the context of coping with serious illness. 11 of these measures were about the parent, of which 5 were specifically about the ill parent. 5 were about the family as a whole. 1 could be used to focus on the child or the adult, and 2 focused on the parent-child relationship. 3 were about the child (of which one focused on a child with an ill sibling and two focused on young carers).

10 measures looked at **communication, expression and social support**. Four were about the child or young person, four were about the parent (of which three were about a well parent and one about an ill parent), and two could be used about a child or parent. Of the six measures which could be used about a child, five were self-reported.

17 measures considered **quality of life and functioning**. This included expectations, functioning by the child, goals, resilience, sense of coherence and quality of life (in many cases, specifically health-related). Eight were about the child, six were about a parent and three could be used about an adult or child. Of the 11 measures that could be used about a child, all included a self-report.

8 measures looked at **self-concept**. 7 were about a child or young person, and one about a parent. All were self-reported.

Table 7: Summary of constructs measured by included studies

Construct	Number of measures			
	Completed by child/young person		All	
	N	%	N	%
Knowledge and attitudes to illness	11	10.6	11	10.6
Benefit-finding in relation to illness	1	1.0	1	1.0
Feelings & attitudes to illness/caregiving	6	5.8	6	5.8
Knowledge of illness	2	1.9	2	1.9
Needs related to illness	2	1.9	2	1.9
Coping	1	1.0	2	1.9
Psychological functioning	21	20.2	33	31.7
Anxiety	3	2.9	4	3.8
Anxiety and depression	2	1.9	4	3.8
Behaviours			1	1.0
Depression	2	1.9	5	4.8
Distress	4	3.8	4	3.8
General mental health	3	2.9	4	3.8
Grief	1	1.0	3	2.9
Internalising/externalising problems	1	1.0	3	2.9
Mood	1	1.0	1	1.0
Positive feelings	1	1.0	1	1.0
Post-traumatic stress	1	1.0	1	1.0
Physical symptoms	2	1.9	2	1.9
Parenting, family functioning and relationships	11	10.6	22	21.2
Caring activities	1	1.0	1	1.0
Family functioning	3	2.9	3	2.9
Family routines			1	1.0
Functioning (ill person)			1	1.0
Impact of caregiving	1	1.0	1	1.0
Parenting	1	1.0	1	1.0
Parenting concerns			1	1.0
Parenting self-efficacy			5	4.8
Parenting style	2	1.9	3	2.9
Psychosocial risk			1	1.0
Relationships	2	1.9	3	2.9
Social functioning	1	1.0	1	1.0
Communication, expression and social support	5	4.8	10	9.6
Communication	1	1.0	3	2.9
Social support	4	3.8	7	6.7
Quality of life and functioning	11	10.6	17	16.3
(Health related) quality of life	5	4.8	9	8.7
(Health related) quality of life of ill person			1	1.0
Expectations	1	1.0	1	1.0
Functioning (child)	2	1.9	2	1.9
Goals	1	1.0	1	1.0
Resilience			1	1.0
Sense of coherence	1	1.0	1	1.0
Wellbeing and functioning (child)	1	1.0	1	1.0
Self-concept	8	7.7	8	7.7
Other			1	1.0
Total	68	65.4	104	100.0

Among the measures included, some seek to capture the specific experiences of children and families coping with serious illness in the family. These include

- **young carers:** Multidimensional Assessment of Caring Activities Checklist (Joseph et al 2009) Positive and Negative Outcomes of Caring Questionnaire (Joseph et al 2009); Young Caregiver of Parents Inventory (Pakenham et al 2006, Cox et al 2014)
- **families where a parent has cancer:** Parenting Concerns Questionnaire (Muriel et al 2012), Cancer Self-Efficacy Scale (Lewis et al 2012); Offspring Cancer Needs Instrument (Patterson et al 2013)
- **families where a parent has serious illness:** Parental Illness Impact Scale (Schrage et al 2004, Morley et al 2010)
- **families where a child has cancer:** Psychosocial Assessment Tool (Kazak et al 2011); Feelings and Attitudes Questionnaire (Sahler and Carpenter 1989), Sibling Cancer Needs Instrument (Patterson et al 2014).

Length of measures

Measures ranged from one to 138 items in length. The longest measures were the parent – report Child Behaviour Checklist (138 items) and its counterpart Youth Self-Report (112 items).

Among self-reported questionnaires for children and young people, the next longest was the Piers-Harris Children's Self-concept scale with 60 items.

Practitioners' survey: assessment and evaluation in practice

Practitioners responding to the online survey (n=18) described how they assess children's needs and decide what support to offer particular children before their close person dies.

Assessing children's needs

Issues they wanted to know about included 'all contextual issues':

- background and previous losses
- progression of the illness
- what the child understands about the situation so far
- how the family are managing, and the Impact on the child of the current situation
- other complicating factors such as mental health difficulties
- whether the child understands what support is and whether they want it.

They used a range of sources to get this information

- **Assessment conversation with the parent/carer** 'Speak with the parent or guardian prior to meeting the children to establish what the child's understanding is so far' (Counsellor, community palliative care service).
- **Assessment conversation with the child** 'We always listen to the voice of the child, ie is it the child that is asking for/wanting support, and check their understanding of what support is' (Counsellor, Hospice)
- **Conversation with referrer**
- 'We do not have an assessment tool, so support for children is dependent on **professional judgement and discussion** with the MDT'. (Social Worker, hospital palliative care team)

We asked which tools, if any, practitioners were using to carry out assessments of children's needs before a death. Those mentioned were the YP Core 10, Revised Child Anxiety and

Depression Scale, Child Outcomes Rating Scale, Strengths and Difficulties Questionnaire, Psyclops, the Winstons Wish family assessment toolkit and in-house assessment forms.

Evaluating support

Practitioners 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

11 practitioners mentioned ways in which they gathered **user feedback** from children and young people and families, as well as indirect feedback from schools. They used evaluation forms, conversations and emails to gather this information. It included feedback on 'what has helped, what didn't help' and also a retrospective rating of change.

Six practitioners described how they measured children's outcomes **before and after** taking part in the service and one described a **session-by-session** method:

Final questionnaire and compare it to the assessment when they first accessed support.

Nurse, hospice

Ask the children how they feel along the way, sometimes through colouring smiley faces.

Counsellor, community palliative care service

The tools which practitioners mentioned for before and after or session-by-session evaluation were the Outcomes Star, Child Outcomes Rating Scale, Revised Child Anxiety and Depression Scale, goal progress sheets, mood scales, smiley faces and theory of change model.

Issues with assessment and evaluation

Scoping review: weaknesses in the evidence base

Most of these reviews identify key methodological challenges and recommend ways in which future research could be strengthened.

Sample size

Many studies have small samples which restrict statistical power and generalizability (Prchal and Landolt 2010, Incedon et al 2015, Zegaczewski, Steiner et al 2017, Hartling 2014), although Walczak et al (2018) report that this may be improving among studies of children facing parental cancer. Prchal and Landolt recommend multi-site collaborative studies to overcome these difficulties.

Follow up

Some evaluation studies only test immediately after the intervention, and lack longer term follow up to find out what happens to the effects of the intervention on children and families over time (Prchal and Landolt 2010, Niemela et al 2010, Incedon et al 2015, Walczak et al 2018)

Different types of intervention

This diversity makes it difficult to pool results and draw conclusions across studies (Ellis et al 2017)

Need for process evaluations

Without an understanding of how a complex intervention worked, it is difficult to disentangle which aspects of it might have been particularly helpful (Prchal and Landolt 2009, Hartling et al 2014)

Setting

Many studies have been conducted in hospitals and clinics rather than in the community, which may bias findings and limit generalizability to different settings (Walczak et al 2018). Further, many studies are from the US, which has a different healthcare system from the UK and findings may not be generalizable to here.

Lack of diversity among participants

- **Cultural understandings of death and bereavement:** studies have largely emerged from Western countries, with few studies including data substantially drawn from minority ethnic or cultural groups. Given known differences in cultural understandings of death and bereavement, this may limit the relevance of findings and models to non-Western countries and to Western countries with increasing cultural diversity (Berggren and Hanson 2016, Kuhne et al 2012, Walczak et al 2018).
- **Diverse family structure:** some interventions with families where a parent is dying have focused on those where the parents are living together with their children. These results may not be generalizable to children living with a terminally ill single parent (Berggren and Hanson 2016; Christ et al 1991), and stepfamilies and blended families may have particular needs (eg children's needs may be very different in single parent families where the resident parent is dying, stepfamilies, and blended families (Berggren and Hanson 2016; Christ et al).
- **Illness type:** several reviewers noted the number of studies on families facing cancer rather than other conditions. HIV and MS have received some attention but there is a lack of studies on the experiences of children living with a family member with other serious illnesses such as MND.

- **Gender:** Steiner et al (2017) noted gender bias among participants in the studies they included. Walczak et al (2018) noted that earlier reviews had been dominated by studies of mothers with breast cancer but that this was not the case in their review.

Control groups, response and attrition rates

Greater use of comparison and control groups is needed so as not to overestimate intervention effects (Hartling et al 2014), and response rates and attrition should be better reported (Walczak et al 2018). Some reviewers did highlight the particular ethical challenges in designing studies on interventions for families where a member is terminally ill, given the limited but unknown time over which families might participate in the study (Steiner et al 2017).

Need for cost outcomes

Some reviews of interventions for siblings of ill children raised the need for economic evaluations (Prchal and Landolt 2009, Incedon et al 2015, Hartling et al 2014) but this was not mentioned by the reviewers of studies where a parent was ill.

Problems with choice of outcome measures

One of the most frequently mentioned concerns to reviewers was the great **diversity of outcome measures** used in different studies, which made comparisons difficult (Prchal and Landolt 2010, Incedon et al 2015). For example, Berggren and Hanson (2016) found five different measures of depression and anxiety used among the 12 studies included in their review.

Researchers also highlighted a **lack of sensitivity and appropriateness** in existing outcome measures (Christ et al 2005) particularly where positive qualitative evaluations were not matched by quantitative measures in the same study (Heiney and Lesesne 1990, Coles et al 2007). Aldefer (2010) also noted differences in the findings of quantitative and qualitative studies on children's experiences of having a sibling with cancer, and recommends the development of outcome measures 'more appropriate to this population' (p80).

In relation to evaluation measures for children where a parent is receiving palliative care, Kuhne et al (2012) suggests that using measures that capture improvement may not be an appropriate fit for families where parent is receiving palliative care, where the goals of support may be more around stabilization and resilience. Berggren and Hanson (2016) note that most of the measures of effectiveness among studies included in their review were of internal psychological symptoms of stress and depression, behavioural problems and issues regarding communication in the family, with few studies evaluating external measures such as the effects of support on children's care burden, social network support and performance at school.

A final issue is around **whose report is included** in the evaluation. Several reviews noted the differences between children and their parents' views about aspects of the child's adjustment and the family's functioning (Packman et al 2005, Knecht et al 2015, Berggren and Hanson 2016). They reiterate the importance of asking children's own views rather than reporting these through proxies, and of getting multiple perspectives.

Practitioner survey: improving assessment and evaluation

Alongside these weaknesses in the published evidence on evaluations, some practitioners in the survey described ways in which they wanted to improve their ways of assessing needs and evaluating support.

Improving assessment

Practitioners were asked if they wanted to change their way of assessing children's needs. Of the 17 who responded, 5 (29.4%) were happy with their current system and did not want to

change. 70.6% (n=12) did want to change. For some, this was to get a better picture of what was going on for the child and family to be able to tailor support accordingly. For others, this was specifically to get a better baseline picture that would be useful in evaluating the service. Suggested ways of improving included forms that were '*more children centred and easier for children to understand*' (Counsellor, hospice); '*more specific to difficulties associated with illness and communication within families*' (Counsellor, NHS CAMHS); '*more formalised*' (Social worker, hospice palliative care team) and '*streamlined*' (Counsellor, hospice).

Improving evaluation

Practitioners were asked if they wanted to change the way they evaluate pre-bereavement support. Three were content with their current methods, and 12 wanted to change. Three wanted to improve but weren't sure how to go about it, raising issues with measurement. Others made specific suggestions including wanting simpler tools, something standardised, something more formal, something that measured outcomes, something that was specific to pre-bereavement working '*asking the right questions*' (Counsellor, bereavement service). Two mentioned wanting something similar to the CBN Child Bereavement Service Questionnaires:

To be able to use the CBN evaluation tool that we already use for our grief project but for our PB [pre-bereavement] project.

Manager, bereavement service

Generic difficulties with evaluation

In the survey responses and focus groups, practitioners raised practical and philosophical challenges to evaluation. Some were generic to evaluating support services for children and families.

Time constraints

Practitioners reported the pressures they were under and how this limited their capacity to carry out extensive evaluations.

Could do this if I had more time. I currently support over 90 families.

Counsellor, palliative care service

There was a strong feeling that any form of evaluation had to be clinically useful as well as generating information for managers and funders.

Feelings about quantitative measures

Participants described not wanting to reduce children and families to tick boxes on a form. There was a reluctance to reduce the complex, messy picture of families' lives to a set of numbers. However, some practitioners did welcome the idea of a measure that would help them gather a range of relevant information about a child and their circumstances relatively quickly and systematically.

Child-friendly forms

Many practitioners mentioned wanting measures that were comprehensible and appealing to children. This related both to the wording of questions (and response options) and to the general layout and look of a questionnaire. They felt this would improve completion rates as well as collecting more useful data, likely to be accurate in its capture of children's views.

Trade-offs between assessment and evaluation

Practitioners identified a tension between a measure that is ideal for assessment, and a measure that is ideal for capturing change towards outcomes. At assessment, it can be

useful to collect as much information as possible to help get a picture of where the child and family is 'at' to help tailor the intervention and to be aware of contextual factors affecting how a child might respond. But not all of these important factors will be modifiable through intervention and so there may be little point in measuring them again at follow-up as they are unlikely to have changed. Only those factors intended to be changed by the intervention should form part of the follow-up measure. Practitioners discussed whether it was better to keep the assessment and follow-up measures exactly the same, or whether to have a comprehensive assessment form and to drop non-modifiable items at follow up.

Whose report matters?

Much discussion focused on the value of multiple reports to help understand the child's situation. They felt it was helpful to capture the child or young person's view, plus that of their parent or carer. They acknowledged that where the ill person in the family was the parent who had been the main caregiver, it could be challenging for a well parent, less used to the caring role, to complete the questions.

Practitioners discussed the reasons why the parent and the child's view of how the child was doing might differ, and suggested that even contradictions provided useful information about communication in the family (eg the child trying to protect the parent from their feelings, the parent worrying unduly about the child or conversely not recognising their needs).

Specific challenges with evaluation

Other difficulties that practitioners mentioned were specific to the context of evaluating support for children before a death.

Dealing with unpredictability

The course of the illness and how a family copes with it is uncertain, and requires flexibility from those supporting the family. Services tend to offer a tailored approach which varies in intensity and focus over time.

Sometimes we will just support the parents/ carers, especially if they have not told the children or are not ready to tell the children. When we do support the children we will offer what they need when they need it. So this might be quite intensive to start with and then lessen if the parents situation changes or improves. However we will adapt according to need as we recognise that this is a very uncertain and unpredictable time for families.

Nurse, hospice

Practitioners identified that this type of flexible intervention is more challenging to evaluate than a clearly defined piece of work such as a series of workshops or a six regular sessions of 1:1 support.

Pre-bereavement support is so unpredictable, so it [evaluation] would have to be very flexible and adaptable.

Nurse, hospice

Accounting for the challenge to come

The biggest challenge raised by practitioners was the practicality of evaluating a preventative intervention during (or shortly after) which a child would face the most significant and challenging of events: the death of a parent or sibling. It is likely if not inevitable that children will feel worse as time goes on.

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

Dramatherapist, Community palliative care service

They contrasted this with typical other interventions aimed at mental health difficulties or family dysfunction, where children arrive with a problem, the aim of the intervention is to reduce or resolve the problem, and the expectation is that the evaluation will show improvement over time.

This challenge, specific to the context of supporting children before a death, has implications for the measures that are used. These need to capture the changes that do happen for children and young people and which are less likely to be affected by the death itself.

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

It also has implications for the timing of the second point of measurement. Practitioners discussed whether this should be before the death, or after it (which would allow comparison with children bereaved suddenly or who hadn't been supported before the death). However, those that offered support before and after the death raised the challenge of attributing change appropriately to these two separate elements.

'The time span [is a challenge] as the review will need to be completed after the death and so perhaps some questions [should be] included around whether the support that was given helped to prepare them?'

Some practitioners raised broader points about the time over which evaluation should take place. In essence, they are helping to prepare children for a change which has life-long implications which will unfold over time.

Did these children grow up to be resilient adults and if so, what part did this intervention play?

Practitioner, focus group

However, the logistical difficulties of longer term follow up (even one or two years) were significant, including having permission to contact families further down the line and losing touch with families if they moved away.

Goal-based measures

In post-bereavement services, goal-based measures are often used to help practitioners tailor the support to the specific needs and wants of the child and their family. There are particular challenges to using these in the context of support before a death.

The difficulty with this is that lots of children want them to not be ill any more or not die.

Teacher, bereavement service.

'How can you know what you don't know?'

One of the key aims that practitioners described was around children having the information they need about the illness and what is happening. But how can this be measured? Specific questions aimed at gauging changes in their age-appropriate understanding of a particular condition would need to be very tailored, and this would pose practical challenges in a busy service supporting children with a wide range of circumstances.

Also, such questions might not tap the specific question at hand. Practitioners felt it would be better to measure whether children and young people felt they had unanswered questions, or whether there was someone they felt confident in approaching if they did.

'The measure mustn't be the messenger'

Children and young people will be in very different circumstances when they first have contact with a pre-bereavement service. Some will be well aware of their parent or sibling's

diagnosis or prognosis, while others will have a sense that something is changed but little knowledge of what is going on. How they are given information and supported to make sense of it is a crucial part of the intervention. This has implications for the wording and presentation of any evaluation forms at baseline or assessment. Practitioners signalled how important it was that forms were introduced carefully and sensitively, but were also aware that in busy services, these might be given out to children and families without a clear awareness of how much the children knew. This meant that the forms must not give or imply information that the child or young person might not yet have.

Draft questionnaires

Practitioners expressed a wish prior to this project, and in the survey and focus groups, that the existing Child Bereavement Service Questionnaires (for evaluating support after a death) should be adapted for use before a death. As no alternative measure that captured the range of relevant outcomes for children across different types of illness had emerged from the review, this was felt to be worthwhile.

Practitioners recommended key adaptations that should be made to the children's questionnaire, the young people's questionnaire and the parent's questionnaire and there was considerable discussion about appropriate wording. The key changes are presented below, along with a rationale.

Table 8a: adaptations made to Child Bereavement Service Questionnaires (child version)

Wording in existing Child Bereavement Service Questionnaire	Adapted wording in new Serious Illness in the Family Service Questionnaire	Notes
After someone dies...	When someone important to us is very ill...	Practitioners discussed 'is dying' but this was felt to be problematic if the child or young person did not actually realise this was the case, and learned of it as a possibility through reading the questionnaire
I've got someone to talk to if I'm worried or sad	I've got someone to talk to if I'm worried or upset	This has been reworded to widen the range of difficult feelings
I feel cross	I feel angry	Practitioners preferred this wording for younger children
I feel sad	I feel scared	More appropriate for before the death
I know what happened when they died	I know what is happening with the illness	This item is intended to tap the child's understanding of the illness and to check they have a narrative that makes sense. It is likely also to be influenced by how involved they feel in what is going on

Table 8b: adaptations made to Child Bereavement Service Questionnaires (young person version)

Wording in existing Child Bereavement Service Questionnaire	Adapted wording in new Serious Illness in the Family Service Questionnaire	Notes
I feel as if I'm the only person this has happened to	I feel as if I'm the only person this is happening to	Reworded to reflect current situation rather than event in the past
There's someone I can ask about how they died, if I need to	I know who to ask about the illness, if I need to	This item is intended to tap social support and communication about the illness
I worry that my feelings are wrong or weird	I worry about how I am feeling	Practitioners didn't want to introduce the idea that feelings could be wrong. This item is intended to tap recognition and acceptance of feelings
I worry about bad things happening	I worry about the future	In the original (post-death) questionnaire, this was intended to tap anxiety about other family members, own health etc. In this (pre-death) version, this is intended to tap anxiety about what will happen (including future treatment, that the person will die, and what will happen after their death).
Thoughts about how they died stop me getting on with things	Thinking about them being ill stops me doing things	In the original (post-death) questionnaire, this was intended to tap intrusive thoughts.
	I am sleeping ok	New item: many practitioners discussed wanting to cover this in discussions with young people. Already reported by parent – needs self-report
Overall, how were relationships in your family <u>before</u> your ... died?	Overall, how were relationships in your family <u>before</u> your ... was ill?	
	I feel supported	New item
	The support I got helped me cope when they died	New item for review form only when young person completes this after the death.

Table 8c: adaptations made to Child Bereavement Service Questionnaires (parent or significant adult version)

Wording in existing Child Bereavement Service Questionnaire	Adapted wording in new Serious Illness in the Family Service Questionnaire	Notes
Please tick if this was a problem before the death	Please tick if this was a problem before the illness in the family	
Worrying that something bad will happen	Worrying about what will happen	
Physical symptoms (stomach-aches, headaches, feeling sick etc)	Physical symptoms (stomach-aches, headaches, bedwetting, feeling sick etc)	Practitioners wanted to include bedwetting
	Change in behaviour	New item to capture changes not otherwise noted
Can talk about the person who died	Can talk about the person who is ill	
Gets bothered or worried by the way other people are grieving	Gets bothered or worried by how others are coping	
Understands their feelings are natural for a bereaved child	Understands their feelings are natural and ok for when someone close is very ill	
Feels able to ask questions about the death or the person who is ill	Feels able to ask questions about the illness and what is happening	
Finds that frightening thoughts about the death interfere with them getting on with things	Finds that frightening thoughts – about the illness and what will happen – interfere with them getting on with things	
Understands what happened in a way appropriate to their age	Understands what is happening in a way appropriate to their age	
	How confident do you feel in talking to your child about what is happening?	New item

Recommendations

For practice

- **Services should articulate the aims of their support for children before a death, and the outcomes they are working towards.** They can use the consensus outcome framework on page 30 to identify the particular outcomes of interest, or use the framework as a whole. This will help them plan, develop and reflect on their practice, inform their choice of outcome measures, and report their effectiveness to families, managers and funders.
- **Services should select outcome measures that are appropriate to their context and aims.** For example, if the main aim of their interventions are to improve communication in the family, they might choose a measure which focused on this. Or if their main concern is to reassure ill parents with cancer, they might select the Parenting Concerns Questionnaire (Muriel et al 2012).
- Services should introduce their baseline/assessment measures as early as possible without disrupting the relationship practitioners are building. While the baseline should be completed as early as possible, this should not be at the expense of building a trusting and positive relationship with the child and family. Practitioners will need to use their judgement to decide when to introduce the measure
- **Services should consider when to do their post-intervention measurement to avoid coinciding with the death.** Some services will be able to complete a review form before the death, others will need to use the post-death review form.
- **Services should collect qualitative feedback as well as quantitative measures.** User feedback, stories and case examples will continue to be valuable tools in evidencing the difference that services make.

For research

- The sector should work together to validate the Serious Illness in the Family Questionnaires (SIFSQs). To achieve a sufficient sample size, this is likely to require a multi-site collaboration.
- Evaluation studies of pre-bereavement support for children should include process evaluations and careful reporting of refusal and attrition rates and (where known) reasons. This will provide helpful information for improving services and making them more relevant and feasible for families coping with serious illness.

For the sector

- **The Childhood Bereavement Network should seek funding for an online platform for the SIFSQs.** This would allow children, young people and parents to complete the measures online. The specification should include local and national reporting facilities
- The Childhood Bereavement Network should approach collaborations working on palliative care outcomes and children's mental health outcomes to introduce the CBSQs and SIFSQs. These discussions should raise awareness of the measures and explore their inclusion in relevant databases and suites of tools.
- The Childhood Bereavement Network should work with funders to help them understand the challenges and possibilities of evaluating this type of support. This would help services negotiate with funders about their expectations of the impact of the work.

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Appendix 1: interventions included in scoping review

Table 9a: Interventions aimed at children (n=19)

Ill person, condition (specifics)	Intervention, Studies (year)	Age of targeted children, n. in study *	Nature of intervention	Intervention aims	Evaluation type (measurement points). Key findings
Close family member, Cancer	Bedway and Smith (1996)	Pre-school to adolescent	Children's group 1 day workshop	Provide safe environment, educate, support and screen children	Qual. Helped with anxiety and created network with peers.
Parent or grandparent, Cancer	Heiney and Lesesne (1996)	5 to 18, studied 12-18 n=11	Children's group 1 day workshop	Facilitate positive coping, increase understanding about cancer, and promote more positive communication about the diagnosis within the family system.	Mixed methods case study (post). Positive evaluation by participants. Children rated hospital tour and increased understanding of cancer as most useful component. Parents reported children's increased knowledge about cancer and openness to talk
Parent or sibling, Cancer or MND (advanced)	The Children's Summer Programme Naudi (2002)	4 to 14, n=25	Summer group activities	Respite for parents, quality time in a safe environment for children, interaction with others	Qual. Reported as helpful to parents and positive for children.
Parent, Cancer (all stages to deceased)	CanTeen Varathakeyan et al (2018)	11 to 26, n=371	Various		Quant. uncontrolled (post only). Compared those who accessed support before and after death. No sig group differences in distress and unmet needs.
Parent, Cancer	Children's Lives Include Moments of Bravery Semple and McCaughan (2013)	5 to 12, children n=7, parents n=6	6 weekly children's group sessions	Provide education about cancer, normalize children's emotions, support communication of emotions, improve coping	Qual. Children learnt about cancer, were able to explore feeling and emotions. Group experience helped normalize emotions and reduce isolation.
Parent, Multiple sclerosis	Fun in the Sun Camp Coles et al (2007)	9 to 14, n=20, parents n=14	Camp	Reduce adverse impact of caregiving and produce better adjustment by increasing knowledge of MS, approach coping, and social support and decreasing avoidant coping and stress appraisal	Quant. uncontrolled (pre, post, 3 month). Children reported sig. decreases in distress, stress appraisals, caregiving compulsion and activity restrictions, and increases in social support and knowledge of illness, no sig. change to coping strategies or family functioning. Parents confirmed increase in children's knowledge of illness, no sig. change in coping strategies, communication skills or adjustment.
Parent, Cancer	Kids can cope Taylor-Brown et al (1993)	5 to 18	6 weekly group sessions for children plus information session for parents	Educate children about cancer, provide a supportive environment, increase coping skills	Qual. Children experienced sense of belonging and recognition of universal and normality of feelings. Learned new coping strategies and dealt with misconceptions and fears.

Parent, Cancer	On Belay Tucker et al (2013)	9 to 19	1 day workshop for children	Build community among children, help children find their personal power	Qual. Helped create social bond between children and normalize experiences. Mastery of challenges and learning to deal with difficult situations.
Parent, Cancer	School based support group Call (1990)	6 to 12	10 children's group sessions	Create safe environment, share feelings, keep on with activities, education about illness	
Sibling, Cancer	Camp Okizu Special and Important Brothers and Sisters (SIBS) Packman et al (2004)	6 to 17, n=77	1 week camp	Address emotional problems, provide peer interaction and validation, and bolster siblings' self-confidence and self-esteem	Quant. uncontrolled (pre, 3-month post). 2004: Improvements in posttraumatic stress symptoms, anxiety, emotional stress, life event stress, QoL and self-esteem. 2005: Health related quality of life sig improved according to child report but not parent report (until controlled for whether the sibling had died).
Sibling, Cancer	Camp Onwards Sidhu et al (2006)	8 to 13, n=26	4 day residential camp	Reduce levels of distress, improve social competence, and improve knowledge about the impact of cancer and its treatment.	Quant. uncontrolled (pre, post, 8 wk follow up). Children reported lower anxiety, increased social competence, increased social acceptance and reductions in fear of disease.
Sibling, Hospitalizations for acute/chronic condition	Education for siblings of hospitalized children Gursky (2007)	6 to 17, IG=25, CG=25	25-35 minute session for child	Increase medical knowledge and reduce anxiety	Quant. non-randomised CT (pre, post). Children in IG reported significantly lower anxiety post-test than controls, and were approaching population norms.
Sibling Chronic illness (child not expected to die <18 months)	Interventions for Siblings: Experience Enhancement Williams et al (2003)	7 to 16, n=79 (full) n=71 (partial), n=102 (waitlist control)	9 group sessions for children plus parent session. Second study also included 5 day residential camp	Increase sibling knowledge about illness, improve social support, self-esteem, attitude, and mood, reduce behavior problems	Quant. 3 group RCT (pre, 5 days, 4 months, 9 months, 12 months). Full intervention group showed improvements in knowledge about illness, behaviour problems, social support, self-esteem, attitude, mood. Partial intervention group improvements in self-esteem and social support. Effects maintained at 12 month follow up.
Sibling, Cancer	Siblings Coping Together Barrera et al (2002, 2004), Salavati et al (2014), Chung (2000)	6 to 18. 2000 n=25; 2002 n=17; 2004 n=47, 2014 n=111	8 weekly group sessions for children	Reduce/prevent emotional and behavioural problems in siblings	Quant. uncontrolled (pre, post). 2000: Children reported improved depressive symptoms and feelings about the illness, no change to anxiety, self-esteem. Parents reported improvements in children's anxiety but not to behaviour, and an increase in fear of cancer. 2002: Children reported significantly decreased anxiety, depression and fear related to cancer and a trend to improved behaviour scores. According to parents' reports, the only significant improvement was in cancer related communication in the family. 2004: Children reported decreased anxiety and depression. Parents reported children's decreased anxiety and improved behaviour

Sibling, Cancer	Structured group intervention for siblings Dolgin et al (1997)	7 to 17, n=24	6 group sessions for children	Improve siblings' cancer-related knowledge, feelings and attitudes towards childhood cancer, and overall mood state	Quant. uncontrolled (pre, post). Children reported improved perception of illness.
Sibling, Special needs (not clear this including life-limiting illness)	Support group for siblings McLinden et al (1991)	School age, n=11 IG=6, CG=5.	6 weekly support groups for children	Provide peer support, a forum for the expression of feelings (both positive and negative), and coping strategies	Quant. RCT (pre, post). Sig difference between IG and CG on perceived social support, but not on behaviour or self-concept.
Sibling, Cancer	Support group for siblings of children with cancer Houtzager et al (2001)	7 to 18, n=24	5 weekly group sessions for children	Enhance control strategies and reduce anxiety	Quant. uncontrolled (pre, post). Siblings reported reduced anxiety after intervention. (Baseline scores were higher than population norms).
Sibling, Cancer (<6 months since diagnosis)	Atherton (1984)	8 to 13, IG n=9, CG=9	2 individual sessions for children	Medical knowledge, coping (cited in Prchal and Landolt 2009)	Quant. RCT (pre, post). No difference in self-reported anxiety scores.
Sibling, Cancer	Cimini (1986)	7 to 14, IG n=15, CG n=15	3 group sessions for children	Medical knowledge, coping (cited in Prchal and Landolt 2009)	Quant. RCT (pre, post). Improvements in children's self-reported anxiety and depression, no change in parents' report of behaviour.

Table 9b: interventions aimed at siblings and ill children together (n=2)

Ill person, condition (specifics)	Intervention, Studies (year)	Age of targeted children, n. in study *	Nature of intervention	Intervention aims	Evaluation type (measurement points). Key findings
Sibling, Chronic illness	Barretstown Gang Camp Kiernan et al (2004)	7 to 16, siblings n=23	10 day residential camp	Improve children's well-being (self-reported physical symptoms, affect, self-esteem, and quality of life)	Quant. uncontrolled (pre, post, 6 months). QoL improved for children but not teens, self-esteem declined but rose at 6 months, no change in physical symptoms or affect.
Sibling, Cancer	Camp Program for Siblings Sahler and Carpenter (1989)	6 to 17, n=90	5 day residential camp	Level of medical knowledge, on the perceptions of how the cancer experience affected the individual, and on the participant's mood state	Quant. uncontrolled (pre, post). 1989: Sig improvements in medical knowledge, intrapersonal feelings about and fear of illness, mood (self- and parent-report), but not in interpersonal perceptions or communication. 1990: younger sibs attending camp for second+ time and older sibs attending for first time showed sig improvements in medical knowledge and trends in reduced fear.

Table 9c: Interventions aimed at parents (n=7)

Ill person, condition (specifics)	Intervention, Studies (year)	Age of targeted children, n. in study *	Nature of intervention	Intervention aims	Evaluation type (measurement points). Key findings
Parent, Cancer	Art Therapy Programme for Children Weiss et al (2005)		22 weekly group sessions	Increase self- confidence, support communication with children	
Parent, Cancer	Being a parent and coping with cancer Hasson-Ohayon and Braun (2011)	0 to 17, parents n=20	4 parents' groups sessions and 1 day workshop	Empower ill and well parent in parenting, help parents to help children adjust and cope	Qual. Parents felt reinforced in chosen ways of coping and supporting children. Felt good about parental role and functioning. Others felt intervention helped to clarify issues and improved understanding of children's responses and their relationships.
Parent, Cancer (breast, stages I-III)	Enhancing connections programme Lewis et al (2015, 2017), Davis et al (2003)	8 to 12, 2015: IG n=90 pairs, CG n=86 pairs. 2017: 32 (within group) 77 (between groups)	5 educational counselling sessions with mothers, exercise book for children. 2017 telephone version tested.	Enhance communication, improve maternal mood, improving parenting behaviour, improve children's adjustment	Quant. RCT (pre, 2, 12 months) (2015) Compared with CG, children showed sig. improvements in behaviour & emotional adjustment at 2 months and remained sig less depressed at 12 months. Mothers showed sig improvements in depressed mood and parenting skills at 2 months but not 12 months. No sig changes to child/maternal anxiety or parenting self-efficacy. Quant uncontrolled (pre, post) 2017 (within subject) sig improvements in maternal anxiety, parenting competencies and child's behavioural/emotional adjustment. Controlled (between subject – compared with 2015 intervention arm). Telephone intervention did as well or better than face to face in improving maternal anxiety, depressed mood, parenting competencies and child's adjustment, and had sig, better impact on maternal confidence.
Parent, Cancer (treatment with curative intent or view to longer term survival)	EPIC - Enhancing Parenting In Cancer Stafford et al (2017)	3 to 12	Psycho-educational DVD, question prompt list and telephone call with clinical psychologist	Improve parenting efficacy and promote family communication, thereby decreasing parental stress and psychological morbidity as well as enhancing children's psychosocial adjustment	
Parent, Cancer (palliative care)	Preventative Intervention for	7 to 17, families n=184 (n=104 completed >=1	6-8 sessions with well parent before the	Facilitate children's adjustment by enhancing surviving parent's capacity to support and care,	Quant. RCT (pre, 8 and 14 months after death). Children in IG reported greater decline in trait anxiety and (non-sig) increase in self-esteem, but no diffs in anxiety and

	Bereaved Children Christ et al (2005)	post-death assessment, IG=79, CG (telephone intervention) n=25).	death, 6-8 sessions after the death	provide safe space for children to express, maintain consistency and stability in children's environment	depression between groups. Parents in IG rated higher by their children in communication and parenting competence.
Parent, HIV	Structural Ecological Systems Therapy Mitrani et al (2010)	6 to 18, n=42, mothers=25	Weekly meetings with mother and her supporter for 4-8 months	Decreasing children's internalizing and externalizing problems and reducing mothers' psychological distress and drug relapse, improve positive parenting and parental involvement	Quant. RCT (pre, post, 4, 8, 12 months). Intervention more efficacious than control condition in reducing children's internalising and externalising behaviours and reducing mothers' psychological distress and drug relapse. Children in IG reported more improvements in positive parenting than those in CG.
Parent, HIV	Teaching, raising and communication with kids Murphy et al (2011)	6 to 12, IG=39 dyads, CG=41 dyads	3 counselling sessions with mother	Enhance family communication and parenting skills specific to disclosure, increase readiness to disclose HIV sero-status and increase disclosure itself, improve maternal and child mental health indicators, improve parent-child relationship and family functioning.	Quant RCT. (pre, post, 3, 6, 9 months). Children in the IG showed reductions in depression and anxiety, and increases in happiness. Mothers in the IG showed increased disclosure of health status, improved disclosure self-efficacy, increased communication with the child, and improvements in emotional functioning.

Table 9d: Interventions aimed at whole families (n=19)

Ill person, condition (specifics)	Intervention, Studies (year)	Age of targeted children, n. in study *	Nature of intervention	Intervention aims	Evaluation type (measurement points). Key findings
Parent, Cancer	Child-parent support group Landry-Dattee et al (2016)	4 to 18, ill parents n=40, spouses n=21, children n=19	2 group sessions for children and parents	Facilitate communication, help support child and their symptoms	Qual. Satisfaction with programme 12 yrs later. Helped facilitate communication about cancer, peer support, parents reported reduced depression in children.
Parent, Cancer	COSIP Denmark Thastum et al (2006)	8 to 15, IG=24 families (24 mothers 17 fathers 34 children), CG=16	5-6 sessions with whole family	Support communication, coping process, parenting competence, improve family functioning, anticipatory grief	Mixed methods. Non-randomised CT (pre, post). (Allocation based on refusal of counselling) and phenomenological analysis. Children and parents sig decrease in depression scores (no increase in fathers' depressive symptoms). Increase in family functioning scores.

Parent, Cancer	COSIP Finland Schmitt et al (2007)	Under 18	5-6 sessions with whole family	Support parenthood, communication, focus attention on children's need, assess need of all family members, accompany family members through loss and grief	
Parent, Cancer	COSIP Germany Paschen et al (2007)	Under 18, n=25	Session with parents, individual sessions with children, possible whole family session	Child level: enhance cognitive comprehension of disease and active coping, legitimate individual needs and feelings, integrate ambivalent feelings towards ill parent, initiate anticipatory grief Parent level: enhance self-perceived competence in parenting, increase well parent's emotional availability to the child Family level: facilitate open communication about the illness, enable flexible handling of divergent needs, prevent children's dysfunctional parentification	Quant. uncontrolled (post only). Families evaluated counselling service positively and were satisfied with goal achievement.
Parent, Cancer (stages I-III, <12 months since diagnosis)	Culturally adapted family intervention Davey et al (2013)	10 to 18 years, children n=19, parents n=12	3 child sessions, two family meetings	Improve family communication and parent/child attachment	Quant. non-randomised CT (pre, post). Greater improvements in family communication in families in intervention group. No changes to symptoms of anxiety or depression.
Parent, Cancer (terminal)	Family focused grief therapy Kissane et al (2006, 2016)	12 upwards, 2006: 81 families (IG=53, CG=28). 2016: 170 families (10 sessions=56; 6 sessions =59; standard care 55).	4-8 sessions with whole family before and after death	Optimize family cohesion, communication and handling of conflict, promote sharing of grief and mutual support	Quant. RCT. (pre, 6, 13 months after death). 2006: Sig differences in 10% of of the most distressed family members in distress and depression. No group differences in distress, bereavement phenomenology, depression, social adjustment, global family functioning. 2016: lower rates of prolonged grief in families in 10 session group than CG at 13 months after bereavement. Better outcomes for low communicating and high conflict families in 10-session than CG.
Parent, Cancer (all stages to deceased)	Family Matters Werner-Lin and Biank (2009)	5 to 11	Concurrent groups for families and children	Facilitate family communication, improve self-esteem and self-efficacy, teach coping skills	Qual. Children and parents better able to communicate needs and feelings. Children and young people stayed on track developmentally, academically and socially.

Parent, Cancer (breast, non-metastasized)	Getting well together John et al (2013)	3 to 14, n=116 pairs	3 weeks: child sessions and mother sessions	Support the family system, prevent at risk children from developing serious emotional and behavioural problems	Quant. within subject CT (pre, post, 3, 12 months). Mothers' emotional functioning, children's psychological health and emotional symptoms showed sig. greater improvements during intervention than during waiting period.
Parent, Cancer	PEPSONE - Cancer Psychoeducational Program for the Social Network Hauken et al (2015)	8 to 18	One 3-hour session	Enhance the family's social network support. This enhanced support will have direct effects on healthy parents' quality of life, mental health, and parental capacity, as well as direct and indirect effects on children's quality of life and mental health	
Parent, Cancer	Short term psychological intervention Hoke (1997)		6-8 family sessions with different groupings	Share concerns and talk about illness, increase understanding and support within families	Qual. case report. Parents reported improved understanding of own responses to illness, recognition of children's concerns & understanding of their experiences
Parent, Cancer	Struggle for life trial Niemela et al (2012)	8 to 17, ill parents n=7, spouses n=7, control group not stated	2 or 6-8 sessions. Child, parent-centred and family sessions	Let's talk (parent focus): strengthen children's protective factors Family Talk Intervention: support family communication, support children and parents' psychosocial wellbeing, planning for the future	Quant. family cluster RCT (pre, post, 4, 10, 18 months). Parents' psychiatric symptoms decreased to same as in general population at 4 month follow up.
Parent, HIV	Teens and adults learning to communicate Rotheram-Borus et al (1997, 2001a, 2001b, 2003, 2004)	11 to 18, baseline adolescents IG=206, CG=207	16 group sessions for children, 5-8 sessions for mothers, mother and child group sessions	Reduce long-term negative social, behavioural, mental health outcomes by increasing coping skills	Quant. RCT (pre, post, 3 month intervals for 24 months, 6 years). 2001a: adolescents in IG reported significantly lower emotional distress, problem behaviours, conduct problems and family related stressors and higher self-esteem than CG at 2 year follow up. Parents in IG reported lower emotional distress and problem behaviours. No diffs in coping style, level of disclosures and legal custody plans. 2001b: IG group showed fewer problem behaviours and sexual partners at 2 years. Intervention didn't impact differently on bereaved and non-bereaved young people. 2003: over 4 yrs, fewer adolescents in IG became teenage parents and their conduct problems were lower. Previously observed lower problem behaviours and emotional distress no longer sig. at 4 years. 2004: over 6 years, IG group more likely to be employed or in school, less likely to receive public welfare, less somatic symptoms, less alcohol consumption.

Parent, Cancer (relapse or metastatic disease)	The Bear Essential programme Greening (1992)	4 to 8, children n=31, parents n=21	Concurrent monthly children and parent groups	Support family in mutual understanding and coping, provide supporting environment	Qual. Parental feedback very positive on enhanced capacity to deal with crisis, improved communication about cancer topics
Parent, Cancer (palliative care)	The Family Support Programme (Family Talks in Cancer Care) Bugge et al (2008, 2009)	5 to 18, children n=12, ill parents n=6, spouses n=7	3 family meetings, parents' meeting, children's meetings	Prevent psychosocial problems and promote coping, by helping to talk about illness, knowledge and security about illness and impact on family life, help to plan for the future	Qual. Children felt more secure, more knowledgeable and aware of own role, family's strengths, and who to approach for help. Parents reported better communication and confidence in parenting competence. Identified resources, shared memory-making and strengthened relationship. Planned for future support needs and palliative care choices.
Parent, HIV	Together for Empowerment Activities Li et al (2011, 2014)	6 to 18, families n=79 (IG n=38, CG n=41) (79 children, 88 parents living with HIV, 79 family members).	6 group sessions for parents, 6 home based activities involving children, 3 community events including children	Improve children's self-esteem, perceived parental care, and problem behavior, reduce depressive symptoms and improve family functioning	Quant. RCT (pre, 3, 6 months), 2014: sig improvements in 6-12 year olds' self-esteem and 6-12 & 13-18 year olds' parental care at 3 and 6 month follow up compared to IG. No sig differences between IG and CG in problem behaviour.
Sibling, Neonates in ICU	Early Visiting to Intensive Care Nursery Oehler and Vileisis (1990)	3 to 12	Early visit to sibling in hospital	Reduce negative child behaviours, increase family functioning, increase knowledge	Quant. RCT (pre, 3 wks). Both groups showed some decrease in negative behaviours. IG but not CG showed sig. decrease in reactive negative symptom and increase in knowledge about newborn. No sig diffs within or between groups on family environment.
Sibling, Cancer	Sibling Support Group Heiney et al (1990)	9 to 15, IG=7, CG=7	7 concurrent group sessions for children and parents	Relieve stress and improve coping	Quant. non-randomised CT (pre, post). No change in social adjustment.
Sibling, Chronic illness or developmental disability	SibLink Lobato and Kao (2002)	8 to 13, n=54	6 group sessions for children over 6-8 weeks	Improving sibling knowledge, sibling adjustment to CI/DD, and siblings' sense of connectedness to other children in similar family circumstances	Quant. uncontrolled (pre, post, subsample 3 month). Post intervention, increases in sibling knowledge of illness and connectedness, decreases in self-reported negative adjustment to the illness and parent reported behaviour problems.
Sibling, Cancer	Dennis (1995)	8 to 13, n=11	10 group sessions for children	Medical knowledge, coping, family communication (cited in Prchal and Landolt 2009)	Quant. uncontrolled (pre, post). Children reported improved medical knowledge, no change to anxiety or self esteem. Parents also reported no change in children's anxiety.

Appendix 2: quantitative measures used in research and practice in support for children when a family member is seriously ill

Table 10a: measures of knowledge and attitudes towards illness (n=11)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Benefit-finding in relation to illness	Benefit-finding*	Pakenham & Bursnall (2006)	Child	Self-report	10 to 25	18	Derived from data collected from adult caregivers of a person with MS. Gains, spiritual growth, and positive changes in personal goals.
Feelings and attitudes to illness/caregiving	Feelings and Attitudes Questionnaire*	Sahler & Carpenter (1989)	Child with ill sibling	Self-report	7 to 17	29	Interpersonal problems, intrapsychic preoccupation, disease-related communication, and disease-related fears experienced by siblings.
Feelings and attitudes to illness/caregiving	Parental Illness Impact Scale*	Morley et al (2010), Schrage et al (2004)	Child with ill parent	Self-report		51	Burden of daily help, Emotional impact, Social impact, Communication & understanding, Impact on personal future, Friends reactions, Parent/child relationship, Global well-being
Feelings and attitudes to illness/caregiving	Perceived Illness Experience Scale*	Eiser et al (1995)	Ill child or sibling	Self-report	8 to 24	40	10 subscales with 4 items: physical appearance, interference with activity, peer rejection, integration in school, manipulation, parental behaviour, disclosure, preoccupation with illness, food and finally, treatment. The last was omitted because it is appropriate for use only with children on maintenance treatment.
Feelings and attitudes to illness/caregiving	Positive and Negative Outcomes of Caring*	Joseph et al (2009)	Young carer	Self-report	9 to 20	20	
Feelings and attitudes to illness/caregiving	Sibling perception questionnaire	Carpenter & Sahler (1991)	Child with ill sibling	Self-report		17	Communication, interpersonal relations, intrapersonal thoughts and feelings, and fear of disease. Communication subscale 5 items: (1) I can talk to my parents about my school work; (2) I can talk to other people my age about my brother's/sister's cancer; (3) I can talk to my parents about my brother's/sister's cancer; (4) I can talk to other adults (like my teachers) about my brother's/sister's cancer; and (5) When my brother/sister got cancer, my parents told me about it.
Feelings and attitudes to illness/caregiving	Young Carers Perceived Stress Scale*	Early et al (2006)	Young carer	Self-report	12 to 18	50	Devaluation of role, personal value of role, overload, social restrictions, family cohesiveness
Knowledge of illness	Cancer-related knowledge*	Carpenter et al (1990)	Child	Self-report	6 to 17	27	
Needs related to illness	Offspring Cancer Needs Instrument*	Patterson et al (2013)	Child	Self-report	12 to 24	47	7 domains: information, family issues, practical assistance, time out, feelings, support (friends) and support (other young people)

Needs related to illness	Sibling Cancer Needs Instrument*	Patterson et al (2014)	Child with ill sibling	Self-report	12 to 24	45	Information, practical assistance, 'time out' and recreation, feelings, support (friends and other young people), understanding from my family, sibling relationships
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Table 10b: measures of coping (n=2)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Coping	Coping Inventory for those with a parent with MS*	Pakenham & Bursnall (2006)	Child with ill parent	Self-report	10 to 25	28	Active coping, seeking social support, positive reinterpretation, acceptance, denial, distraction, and wishful thinking.
Coping	Coping with illness (HIV)*	Namir et al (1987)	Parent (ill)	Self-report		37	5 subscales: self-destructive escapism, passive problem solving, passive action, spiritual hope, seeking social support

Table 10c: measures of psychological functioning (n=33)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Anxiety	Fear Survey Schedule for Children - Revised	Ollendic (1983)	Child	Self-report	7 to 16	30	
Anxiety	Revised Child Manifest Anxiety Scale	Reynolds & Richmond (1978)	Child	Self-report	6 to 19	37	Total anxiety and the 4 sub-scales: worry/oversensitivity, physiological anxiety, social concerns/concentration and a lie scale
Anxiety	State-trait Anxiety Inventory for Children (STAIC) /Adolescents (STAIY)	Spielberger et al (1983)	Child	Self-report	9 to 12 and 12+	40	Both measures contain 20 items tapping state anxiety and 20 items tapping trait anxiety
Anxiety	State-trait Anxiety Inventory	Spielberger et al (1983)	Parent	Self-report		20	

Anxiety and depression	Physiological Hyperarousal and Positive and Negative Affect Scale for Children	Clark & Watson (1991)	Child	Self-report	6 to 17	48	15 items measure positive affect, 15 items measure negative affect and 18 physiological hyperarousal
Anxiety and depression	Revised Children's Anxiety and Depression Scale	Chorpita et al (2000)	Child	Self- and parent-report	8 to 18	47	Total anxiety and low mood score and separate scores for each of the follow sub-scales: separation anxiety; social phobia; generalised anxiety; panic; obsessive compulsive; total anxiety; and, low mood
Anxiety and depression	Depression-anxiety Stress Scale Short Form	Lovibond & Lovibond (1995)	Adult	Self-report		21	Set of three self-report scales designed to measure the negative emotional states of depression, anxiety, and stress.
Anxiety and depression	Structured Interview Guide for the Hamilton Anxiety and Depression Subscales	Williams (1988)	Adult	Parent-report			Semi-structured interview
Behaviours	Missouri Behavioural Checklist	Sines et al (1969)	Child	Parent-report		70	Children's behaviour, aggression, inhibition, activity level, sleep disturbance, somatization, sociability
Depression	Beck Depression Inventory for Youth	Beck et al (2001)	Child	Self-report	7 to 18	20	Items reflecting children's negative thoughts, feeling of sadness and physiological indications of depression. Self-concept, anxiety, depression
Depression	Children's Depression Inventory	Kovacs (1992)	Child	Self-report	7 to 17	27	Negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem
Depression	Beck Depression Inventory	Beck et al (1996); Beck & Beck (1972)	Adult	Self-report		21 (13)	
Depression	Center for Epidemiological Studies Depression Scale	Radloff (1977)	Adult	Self-report		20	Emphasis on depressed mood during the last week
Depression	Zung Self-rating depression scale (short version)	Zung (1965)	Adult	Self-report		9	Asked how felt in 9 different situations
Distress	Brief Symptom Inventory	Derogatis (1993)	Adolescent or adult	Self-report	13+	53	Global scale, anxiety subscale, depression subscale

Distress	Distress Thermometer	CAU National Comprehensive Cancer Network (2003)	Child or adult	Self-report	1	Based on pain scales
Distress	General Health Questionnaire	Goldberg & Williams (1988)	Adolescent or adult	Self-report	12	Focuses on breaks in normal functioning rather than on life-long traits; therefore, it only covers disorders or patterns of adjustment associated with distress
Distress	Kessler-10	Kessler et al (2002)	Adolescent or adult	Self-report	10	
General mental health	Strengths and Difficulties Questionnaire	Goodman (1997)	Child	Self- and parent-report	11 to 16	25 Emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. For parents of 3- and 4-year-old children, the questionnaire is slightly modified: 22 items are identical, the item on reflectiveness is softened, and items on antisocial behavior are replaced by items on oppositionality.
General mental health	Symptom Checklist 90	Derogatis (1973)	Adolescent or adult	Self-report	13+	90 Somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism. Additional items which helps clinicians assess other aspect of the clients symptoms eg poor appetite.
General mental health	YP CORE-10	Twigg et al (2010); Twigg et al (2016)	Child	Self-report	11 to 16	10
General mental health	Rand Mental Health Inventory	Veit & Ware (1983)	Adult	Self-report	38	Anxiety, depression and loss of emotional control, positive affect and emotional ties
Grief	Complicated Grief Inventory*	Prigerson et al (1995)	Adolescent or adult	Self-report	Here used 12+	
Grief	Bereavement phenomenology questionnaire*	Byrne & Raphael (1994)	Adult	Self-report	22	
Grief	Texas Revised Inventory of Grief*	Faschinbauer et al (1977)	Adult	Self-report	13	
Internalising/externalising problems	Youth Self-report	Achenbach & Rescorla (2001)	Child	Self-report	11 to 17	112 Externalising and internalising (from anxious/depressed, withdrawn/depressed, somatic complains, social problems, thought problems, rule-breaking behavior, and aggressive behavior)
Internalising/externalising problems	Child Behaviour Checklist	Achenbach et al (1983)	Child	Parent-report	138	Total Behavior Problem score (118 items) and a Total Social Competence score (20 items), as well as scores on two broad-band behavioural syndromes (internalizing and externalizing), several age and gender-specific narrow-

							band behavioral syndromes, and three specific social competence subscales (activities, school, and social competence).
Internalising/externalising problems	Revised Behavior Problems Checklist	Quay & Peterson (1987)	Child	Parent-report		89	The conduct disorder, socialized aggression, and attention problems subscales were combined into an externalizing scale. The anxiety-withdrawal subscale alone served as a measure of internalizing.
Mood	Mood questionnaire*	Sahler & Carpenter (1989)	Child with ill sibling	Self- and parent-report	7 to 17	14	
Physical symptoms	Physical Symptoms Inventory*	Kiernan et al (2004)	Child	Self-report	7 to 16	30	
Physical symptoms	Somasick scale	Boyle et al (1987)	Adolescent	Self-report		17	
Positive feelings	Bradburn Affect Balance Scale (modified)	Bradburn (1969)	Child or adult	Self-report	Here used 9+	8	3 additional items (cheerful, inspired, satisfied) added to Bradburn's original five positive items. His scale had an additional 5 negative items
Post-traumatic stress	UCLA PTSD Index for DSM-IV	Rodriguez et al (1998)	Child	Self-report	7 to 12; 13 and up	24 (22 for adolescents)	A categorical diagnosis of none, partial, or full PTSD can also be calculated using this instrument.

Table 10d: measures of communication, expression and social support (n=10)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Communication	Parent Adolescent Communication Scale	Barnes & Olson (1985)	Parent and child	Self- and parent-report		10	
Communication	Disclosure self-efficacy scale*	Murphy et al (2011)	Parent (ill)	Self-report		9	Level of confidence to disclose HIV status to child developed for Murphy et al (2011)
Communication	Family-Peer Relationship Scale	Ellison (1983)	Child	Parent-report		6	The measure has two subscales relevant to the current study: Disclosure of Negative Feelings, for example, "How likely is it that the child will share if s/he is feeling mad or angry?" and Disclosure of Bad Things Happening, for example, "How likely is it that the child will share if something bad happens to the child?"
Social support	Brief Social Support Questionnaire	Sarason et al (1987)	Child or adult	Self-report	Not specified - here used 9+	6	Who children count on in 6 different circumstances, and how satisfied with this support.
Social support	Nurse-sibling Social Support Questionnaire*	Murray (2000)	Child with ill sibling	Self- and parent-report	7 to 12	30	Emotional, informational, instrumental and appraisal support
Social support	Social support scale	Harter (1985b)	Child	Self-report	8 to 18	24	4 subscales with 6 items each concerned with support from parents, classmates, teachers, and close friends
Social support	Who helps me*	McLinden et al (1987)	Child	Self-report		11	
Social support	Assistance Questionnaire - Recievers*	Dyregrov et al (2003)	Parent (well)	Self-report		7	Adults' experiences and need of social support related to the situation caused by the cancer.
Social support	Crisis support scale	Joseph et al (1992)	Parent (well)	Self-report		7	
Social support	Multi-dimensional scale of Percieved Social Support	Zimet et al (1988)	Parent (well)	Self-report		4	

Table 10e: measures of quality of life and functioning (n=17)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
(Health related) quality of life	Child Health Questionnaire	Landgraf et al (1996)	Child	Self- and parent-report	10 to 18	87 (self); 98, 50,28 (parent)	11 domains. Physical functioning, bodily pain, role/social-physical, general health perception, role/social-emotional/behaviour, mental health, general behaviour, self-esteem, parental emotional impact, parental time impact, family impact
(Health related) quality of life	Kidscreen	The Kidscreen Group Europe (2006)	Child	Self- and parent-report	8 to 18	52/27/10	10 (5) dimensions: physical well-being, psychological wellbeing, moods and emotions, self-perception, autonomy, parent relation and home life, social support and peers, school environment, social acceptance (bullying), financial resources.
(Health related) quality of life	KINDL	Ravens-Sieberer (2003)	Child	Self-report	4 to 6, 7 to 13 and 14 to 17	24	6 dimensions: Physical well being, emotional well being, self-esteem, family, friends, and everyday functioning. Also global score
(Health related) quality of life	Pediatric Quality of Life Scale	Varni et al (1999)	Child	Self-report	8 to 12	23	"(a) physical health, (b) emotional health, (c) social functioning, and (d) school functioning#"
(Health related) quality of life	Satisfaction with life scale	Pavot & Diener (1993)	Child or adult	Self-report		5	
(Health related) quality of life	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire*	Aaronson et al (1993)	Adult (ill)	Self-report		30	Five multi-item functioning scales, one 2-item global health/QoL assessment, and nine symptom scales.
(Health related) quality of life	Inventory for Quality of Life in Children and Adolescents (ILC)	Mattejat & Remschmidt (2006)	Adult	Self-report		7	Six relevant areas and an additional global rating

(Health related) quality of life	Medical Outcome Study Short Form 36	Ware et al (1994)	Adult	Self-report	36		Physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions. Single item perceived change in health
(Health related) quality of life	QOL scale	Burckhardt & Anderson (2003)	Adult	Self-report	16		(1) physical and material well-being; (2) personal development; (3) relationships with others; (4) participation in social activities; (5) participation in community and civic activities; and (6) recreation.
(Health related) quality of life of ill person	Functional Assessment of Cancer Therapy-General*	Cella et al (1993)	Adult (ill)	Self-report	33		Composite of subscales relating to physical, social, emotional, and functional well-being.
Expectations	Personal expectations	McLoyd et al (1996)	Adolescent	Self-report	11 to 18	11	3 subscales: overall expectations, expectations for finding a partner or a spouse with a good job, likelihood of pregnancy or parenthood outside of marriage
Functioning (child)	Child Outcome Rating Scale	Duncan et al (2003)	Child	Self-report	6 to 12	4	The CORS was developed for children age 6–12. It has the same format as the ORS but with more child friendly language and smiley and frowny faces to facilitate the child's understanding when completing the scales (Duncan et al., 2003).
Functioning (child)	Outcomes Rating Scale	Duncan et al (2003)	Adolescent or adult	Self-report	13+	4	Symptom distress, interpersonal well-being, social role, overall well-being
Goals	Goal based questionnaire	Law and Jacob (2015)	Child	Self- and parent-report			
Other	Outcomes Star	Mackeith (2014)	Child	Self-report			
Resilience	Dispositional Resilience Scale-Revised	Hystad et al (2010)	Adult	Self-report		15	Domains of commitment, challenge and control
Sense of coherence	Sense of Coherence	Antonovsky (1993)	Adolescent	Self-report	Not clear	29 and 11	11 comprehensibility, 10 manageability and 8 meaningfulness items.

Table 10f: measures of self-concept (n=8)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Self-concept	Beck Self-concept Inventory for Youth	Beck et al (2001)	Child	Self-report	7 to 18	20	Items include self-perceptions, such as competence, potency and positive self-esteem
Self-concept	Children's Self-Image Scale	Rosenberg & Simmons (1972)	Child	Self-report	Under 13	6	
Self-concept	Piers-Harris Children's Self-concept scale	Piers & Piers-Harris (1984)	Child	Self-report	7 to 18	60	Behavioral Adjustment, Intellectual and School Status, Physical Appearance and Attributes, Freedom From Anxiety, Popularity, Happiness and Satisfaction plus 2 scales measuring inconsistent answers and response bias
Self-concept	Rosenburg self-esteem scale	Rosenberg (1965)	Adolescent or adult	Self-report		10	
Self-concept	Self-esteem inventory - short form	Coopersmith (1984)	Child	Self-report	8 to 15	25	Areas of experience (social, academic, family, and personal) likely to interact with the self-esteem of children.
Self-concept	Self-perception Profile for Adolescents	Harter (1988)	Adolescent	Self-report	14 to 19	48	6 subscales as in children's version, but also 3 additional ones to reflect the concerns of adolescents, namely job competence, romantic appeal and close friendship
Self-concept	Self-Perception Profile for Children	Harter (1985a)	Child	Self-report	8 to 13	36	6 items in each: global selfworth, scholastic, social, athletic, and physical appearance. Behavioural conduct subscale taps the degree to which children like the way they behave, do the right thing, act the way they are supposed to, and avoid getting into trouble.
Self-concept	Self-Report of Personality	Reynolds & Kamphaus (1992)	Child	Self-report	8 plus	186	A subtest of the Behaviour Assessment System for Children (BASC) 50. Stidy reported on the personal adjustment subscale

Table 10g: other measures (n=1)

Construct	Name of measure	Reference	Who is it about?	Whose report	Age if child-report	No. item	Subscales/notes
Experiences	Coddington Life Events Scale	Coddington (1999)	Parent	Parent-report			

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