Communication with Children and Adolescents about the Diagnosis of a Life Threatening Condition in their Parent

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Many adults diagnosed with a life threatening condition have children living at home; they and their partners face the dual challenge of coping with the diagnosis while trying to maintain a parenting role. Parents are often uncertain about how, when and what to tell their children about the condition and are fearful of the impact on their family. There is evidence that children are often aware that something is seriously wrong and want honest information. Healthcare professionals play a key role in supporting and guiding parents and caregivers to communicate with their children about the diagnosis. However, the practical and emotional challenges of communicating with families are compounded by a lack of evidence-based guidelines.

This narrative review considers children's awareness and understanding of their parents' condition, the effect of communication around parental life threatening condition on their wellbeing, factors that influence communication and the challenges to achieving effective communication. Children's and parents' preferences about communication are outlined. An expert workshop was convened to generate principles for healthcare professionals, intended as practical guidance in the current absence of empirically-derived guidelines.

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Introduction

Many adults diagnosed with a life threatening condition (LTC) are parents with children living at home. In the USA alone it is estimated that 2.85 million children (age 18 years or younger) are living with a parent who has been diagnosed with cancer.[1] In low and middle income countries (LMICs) LTCs affect even more families; the World Health Organisation (WHO) estimates 70% of deaths from cancer worldwide occur in LMICs.[2] Life threatening infections such as HIV are also more common in LMICs with sub-Saharan Africa the most severely affected; nearly 1 in every 25 adults (4.2%) are living with HIV and in parts of Southern Africa over a quarter of pregnant women are HIV-positive.[3] With Prevention of Mother to Child Transmission programmes, the vast majority of their children are HIV-negative but are born into families where at least one parent is HIV-positive. Although treatment advances for HIV have markedly improved long-term prognosis, daily medication and frequent clinic appointments are still required. Furthermore, over one million people died of HIV in 2016, largely due to lack of access to adequate treatment.[4]

Parental LTCs have an impact on the physical, social and emotional wellbeing of children. A large cohort study of over 60,000 children in Finland found significantly higher use of psychiatric services by children who had been affected by parental cancer before the age of 21 years.[5] In low income settings, parental illness and/or death can even impact on child survival; in rural South Africa the risk of mortality for children under five increased both after their mother had died *and* in the months *before* her death.[6] Parents with LTCs face the dual challenge of coping with their diagnosis and treatment, while simultaneously maintaining their caregiving role. Parents may feel unsure about how to talk to their child and how much information to share with them, while also wanting to protect their child from distress. Parents would benefit from clear guidance and support from healthcare professionals (HCPs) about how to approach these topics with their children. However, when a parent is ill, HCPs involved are primarily focussed on the adult patient. They may never have direct contact with the patient's children or be aware of the impact of the illness on the wider family. Indeed, many may be unsure about whether considering the needs of the patient's children forms part of their role. It can be difficult for HCPs treating adults to raise the issue of children's understanding of parental illness and the importance of communicating with them about the illness; this can deny parents much needed resources and support. Empirically based, parent/caregiver-focused recommendations are largely lacking,[7] making this emotionally challenging task especially difficult for HCPs.

Aim of the review

Given the scale of the global burden of LTCs affecting parents, and the absence of evidence-based guidelines to support HCPs and families to communicate the diagnosis to children, the available literature was examined with the aim of addressing four main questions:

1) What is the evidence that communication with children about parental LTC is important?

2a) What is the impact of communication on children and adolescents' emotional, behavioural and health outcomes? 2b) What is the impact of communication on parents and the wider family system?

3a) What factors influence the process of communication? 3b) What are the barriers and challenges to communication?

4) What are the reported preferences of children, adolescents and parents about the way diagnosis and information is conveyed?

The outcomes of the narrative review and previously published recommendations[8] formed the basis of discussion at a workshop of international experts in 2017 to generate a framework of communication principles to address the lack of evidence based guidelines.

Methods (see appendix)

Results

Findings of the review

In HICs research has largely focused on the experience of children and parents with cancer. In contrast, issues around HIV/AIDS disclosure have dominated the research from LMICs. Practical and ethical considerations have influenced research methodology, with much of the work conducted through observational studies, qualitative interviews, retrospective self-report and intervention studies, rather than randomised controlled trials (RCTs). Most studies in HICs involve parents/caregivers and children, whereas those in LMICs are informed almost exclusively by parents/caregivers and rarely involve children directly. Furthermore most of the communication provided by HCPs is with the parent, in order to help them talk to their children, rather than with children directly.

Relevant articles are summarised in table 1, with table 2 detailing the intervention studies (see appendix).

1) What is the evidence that communication with children about parental LTC is important?

The literature identifies several compelling reasons to encourage parents, supported by HCPs, to discuss their illness openly with their children including:

i) children often have an awareness of changes to their parents' health even if they have not been formally told

Children are very observant and may notice their parents' physical deterioration and/or be aware their parent is taking medication or going to clinic. A Chinese quantitative survey of children (n=626; 6-17yrs) found that only a minority (31-39%) heard their parents' HIV status from the parents themselves, yet of those who were *not* told by their parents, 85-88% were aware of their parents' diagnosis or illness through their own observations or from other people.[9] In Botswana (n=32; 5-18yrs) a third of HIV-positive parents thought that their child had guessed their HIV-positive status.[10] A qualitative study in Zimbabwe (n=56 orphans; 7-22yrs) found that many bereaved adolescents partially knew, or strongly suspected that their parents were HIV-positive although few had been formally told.[11] Children often felt unable to ask about the changes they have noticed in their parents

leading to tension and anxiety.[12] A qualitative study (n=28; 3-18yrs) in the USA reported that even young children demonstrated an awareness of their parent's medical condition (e.g. a three-year-old drawing pictures of her mother with and without hair following chemotherapy) and its implications.[13] A UK-based qualitative study of mothers with breast cancer (n=37) and their children (n=31; 6-18yrs) found that some of the younger children (age 6 years) were aware of cancer as a LTC and had suspected something was seriously wrong before they were told the diagnosis.[14]

ii) children often wish to know about their parents' illness

Research consistently highlights the need for communication with children in a timely manner and the potential negative consequences when information is absent. A quantitative study in Sweden of young adults bereaved 6-9 years earlier during their adolescence (n=622; 13-16yrs) found that 98% thought that teenage children should be informed when their parents' death was imminent, although only 59% had themselves been told.[15] A qualitative study in the UK of adults (n=33) who had experienced the death of a parent during childhood (13mths-17yrs), reported that their distress had been compounded by a lack of accurate information about their parent's death.[16] A Danish qualitative study involving parents with cancer and their children (n=21 children from 15 families; 8-15yrs), reported that with the benefit of hindsight, parents who had allowed some time to elapse before disclosing their diagnosis regretted this decision and felt that their children had reacted negatively to not being told earlier.[17]

iii) in the absence of information children can misinterpret parental symptoms and construct their own (mis)understanding, leaving them distressed and emotionally isolated

When children are not given information about their parent's illness, they attempt to make sense of the situation on their own. Children's beliefs can be "more dire than the truth" and it is essential to dispel misconceptions and "magical thinking"[18,19] (see review of child LTC for developmental stages of children's understanding of illness and death). Clear communication can help children prepare for changes and/or loss enabling them to receive support.[20] An absence of information may result in:

a. misinterpretation of parental symptoms; hair loss and other side effects of treatment can be wrongly interpreted as deterioration in their parent's condition, and adequate explanation can provide reassurance.[21,22]
b. children relying on their own observations to construct their reality; in an Ugandan study adolescents (13-19yrs) who were not told their parent had died of HIV/AIDS, attributed the death to either a treatable condition or a spiritual cause.[23]
c. children worrying that they have caused the illness.[14,18,24] In a US study, children aged 7-11 years (n=87) attempted to understand their parent's illness through links with unrelated events.[18] Bereaved adolescents (13-18yrs) in another US study (n=11) reported that insufficient or distorted information resulted in feelings of regret and guilt about their possible role in causing or failing to prevent the death.[25]
d. children worrying about their own health and risk of developing a similar condition.[14,18,24]

2a) What is the impact of communication on children and adolescents' emotional, behavioural and health outcomes?

Research has explored the relationship between communication about a parent's illness and children's psychological symptoms, with many studies indicating the benefits of communication for children.

A longitudinal study in the USA assessed outcomes for HIV-positive mothers and their HIV-negative children (n=135; 6-11yrs).[12] During the study a number of mothers disclosed their HIV status to their children. Analyses indicated a trend towards lower anxiety and a significant decrease in symptoms of depression in the children following maternal disclosure.[12] Children whose mothers disclosed their diagnosis also reported lower levels of negative self-esteem (child-reported)[26] and lower levels of aggressiveness (maternal-report)[12] compared with children of non-disclosing mothers.

Positive family relationships were associated with lower anxiety and depression in adolescents (n=50; 12-19yrs) whose parent had cancer in a USA study.[27] The relationship between anxiety and family cohesion was mediated by the extent to which family members expressed their thoughts and feelings (adolescent-report).[27] A quantitative study in the UK of adolescents (n=56; 11-17yrs) and their mothers with early stage breast cancer found adolescents had higher total problem scores, both internalising symptoms (anxiety/depression symptoms) and externalising behaviours, that were significantly associated with poor communication generally.[28] A mixed methods study of children in Israel (n=44; 6-16yrs) found that those who had been explicitly told the name of their parent's illness (cancer) and its serious nature had significantly lower levels of anxiety.[29]

A Dutch quantitative study of adolescents and young adults (n=284; 11-23yrs) who had a parent with cancer found that daughters who perceived their parent's illness to be more serious had higher levels of stress, although this association was not found for sons.[30] This study did not compare children's perceptions of seriousness to clinical ratings of disease severity, but concluded that it is important to ensure children's perceptions are accurate to minimise unnecessary anxiety.[30]

Research has also explored the relationship between communication and symptoms of post-traumatic stress disorder. Problems in communication with either an ill or a healthy parent (in families where one parent has cancer) were associated with greater symptoms of post-traumatic stress in adolescents (n= 212; 11-18yrs) in the Netherlands.[31] Issues such as an absence of sharing feelings or avoiding talking about particular topics with either their ill, or healthy parent, were significantly related to higher scores on the avoidance subscale and total distress on the Impact of Events Scale, for both sons and daughters. Sons also reported more intrusive and distressing thoughts when communication was problematic.[31] Open communication (quality of exchanging information, freedom in communication, comprehension and satisfaction with communication) between daughters and their healthy parents was associated with fewer symptoms of intrusion, avoidance and total distress.[31]

While there are many studies supporting the value of talking with children about a parent's LTC, this is not universal. A quantitative study in the UK with children and adolescents (n=80; 8-16yrs) who had a parent with cancer found no association between measures of child adjustment (child-rated anxiety and maternal ratings of child behaviour) and communication.[32] Similarly, a quantitative study in Greece of parents (n=101) and children (n=56; 4-17yrs) in which one parent was affected by multiple sclerosis found no association between communication around illness and family functioning.[33] However a South African study found that mothers (n=103) disclosure of HIV diagnosis to their

adolescents (11-16yrs) was associated with an increase in behavioural, but not emotional problems.[34] Nonetheless the strongest predictors of behavioural problems were family factors, with fewer symptoms reported in children with better parent-child and inter-parental relationships.[34]

The relationship between psychological wellbeing and communication may be more nuanced over time. An observational study of the impact of HIV disclosure on adolescents (n=395; 11-18yrs) in the USA found that problem behaviours (unprotected sex, alcohol use, drug use and contact with criminal justice system) were higher in adolescents who knew their parents HIV status at the time of recruitment to the study.[35] However, there were significant differences in the trajectory over the following 5 years with problem behaviours decreasing over time among the disclosed children and increasing amongst the non-disclosed children.[35]

Research has examined the relationship between the amount of information given to children and psychological outcomes. The Greek study outlined above (n=56; 4-17yrs) found that children who had *partial information* about parental multiple sclerosis (e.g. they were aware of a parental health problem but had limited, unspecific or 'developmentally inadequate' information) had more social and emotional difficulties compared to children who had been given either *no information*, or *total disclosure* about their parent's condition. In a cross-sectional study in South Africa of HIV-positive mothers (n=395) with children aged 6-10 years, only 29 had been informed of their mother's HIV status and 18 had received *partial disclosure* (told that their mother was sick). This latter group had fewer internalising and externalising behaviours and improved skills of daily living, compared to those who had been *told nothing*.[36] However there was no such association for those explicitly told about HIV compared to the non-disclosure group. The differences between these two studies may reflect the specific complexity of HIV disclosure, although the small sample sizes limit the interpretation.

Evidence drawn from intervention studies

Intervention programmes for families experiencing parental LTCs have sought to facilitate communication between parents and children (Table 2 appendix). Evaluation of these programmes provides some evidence of their benefit, although identifying the specific elements responsible for positive outcomes remains difficult.

The Enhancing Connections programme in the USA for mothers with cancer (n=176) included sessions to develop the mother's listening skills, understanding the child's experience as distinct from her own, and strategies to encourage the child's emotional expression.[37] Significant reductions were seen in both child (8-12yrs) behavioural and emotional problems post intervention. Improvements in parent-child communication were found in a pilot RCT (TRACK) in the USA which aimed to help with communication skills for HIV-positive mothers (n=80) and provide practical advice on disclosure.[38] Children (6-12yrs) showed improvements in anxiety, depression and happiness scores, although only 33% of mothers actually disclosed during the study. Evaluation of an uncontrolled five/six session intervention in Denmark aiming to facilitate open communication about illness for parents with cancer (n=41 adults, n=34 children) indicated a significant decrease in depression scores for children (8-15yrs) post intervention.[39] An intervention, beginning prior to parental death, in the USA which included work on family communication (n=184 children and parents) found no significant differences in children's emotional symptoms between intervention and control groups.[40] However, from pre-

bereavement to 6 months after death, greater decreases in child (7-17yrs) anxiety and depression scores were reported for the intervention arm.

An RCT in the USA with parents diagnosed with HIV/AIDS (n=307) and their adolescents (n=412; 11-18yrs) compared an intervention to improve behavioural and mental health outcomes of adolescents and their parents relative to standard care.[41] The initial eight parent-only sessions focussed on coping with illness and disclosure. The sixteen subsequent parent and adolescent sessions included: parental awareness of children's needs, making custody arrangements and resolving conflicts. Adolescent topics included disclosure of a parent with HIV/AIDS, dealing with stigma and encouraging safer sex. The intervention group had significantly better adolescent outcomes (adolescent-report): lower levels of emotional distress and family-related stressors, fewer behavioural problems and higher levels of self-esteem than the control group at 24-months follow-up. Parents in the intervention group had lower levels of emotional distress and fewer problem behaviours relative to the control group.[41] For both groups, levels of disclosure were high; at study entry 71% had disclosed to at least one adolescent within the family, and at the 2 year follow-up disclosure had increased to over 85% of all adolescents in the family.

Interventions to facilitate communication about parental LTC (specifically HIV) have been evaluated in LMICs. In a rural South African population with high levels of HIV, a RCT (n=464; 6-10yrs) was conducted to test whether an intervention ('Amagugu'), consisting of six home-based counselling sessions delivered by lay counsellors increased HIV disclosure by HIV-positive mothers to their HIV-negative children.[42] The intervention included a session for the mother to help her emotionally process the impact of the diagnosis on herself and anticipate children's common reactions and questions following disclosure.. During the sessions the mother and counsellor identified other people with whom the child could discuss HIV. Materials provided to the mother included a 'Body Map' to explain HIV in an age appropriate, non-stigmatising manner. The control group received an enhanced standard of care which included one clinic-based counselling session to promote disclosure. The intervention group was found to have higher rates of maternal HIV disclosure, and improvements in healthcare engagement, care planning for the child and the mother-child relationship. There were no differences between the groups for maternal and child mental health outcomes. However, subsequent analysis showed that where disclosure was undertaken, irrespective of group, it was associated with improvements in maternal and child mental health.[42]

A pilot RCT in Rwanda (n=82 families; 170 children; 7-17yrs) compared a family strengthening intervention (FSI) to treatment-as-usual (TAU).[43] The FSI aimed to improve family communication and child mental health, and promote disclosure of parental HIV to children. The intervention consisted of an introductory session and six home-based modules addressing psychoeducation about HIV, communication skills, problem solving and developing a social support network. Parents and children had separate meetings involving psychoeducation and role plays to prepare for a family session to develop a narrative of the family's strengths. At follow-up there were reductions in children's depression scores compared to TAU, but there were no differences in conduct problems or parenting scores.[43] Parenting and family unity initially decreased but "resolved" over time. The authors suggested this may reflect an initial loss of trust and associated challenges in the family relationship, which is then mitigated by the family-based intervention.[44]

2b) What is the impact of communication on parents and the wider family system?

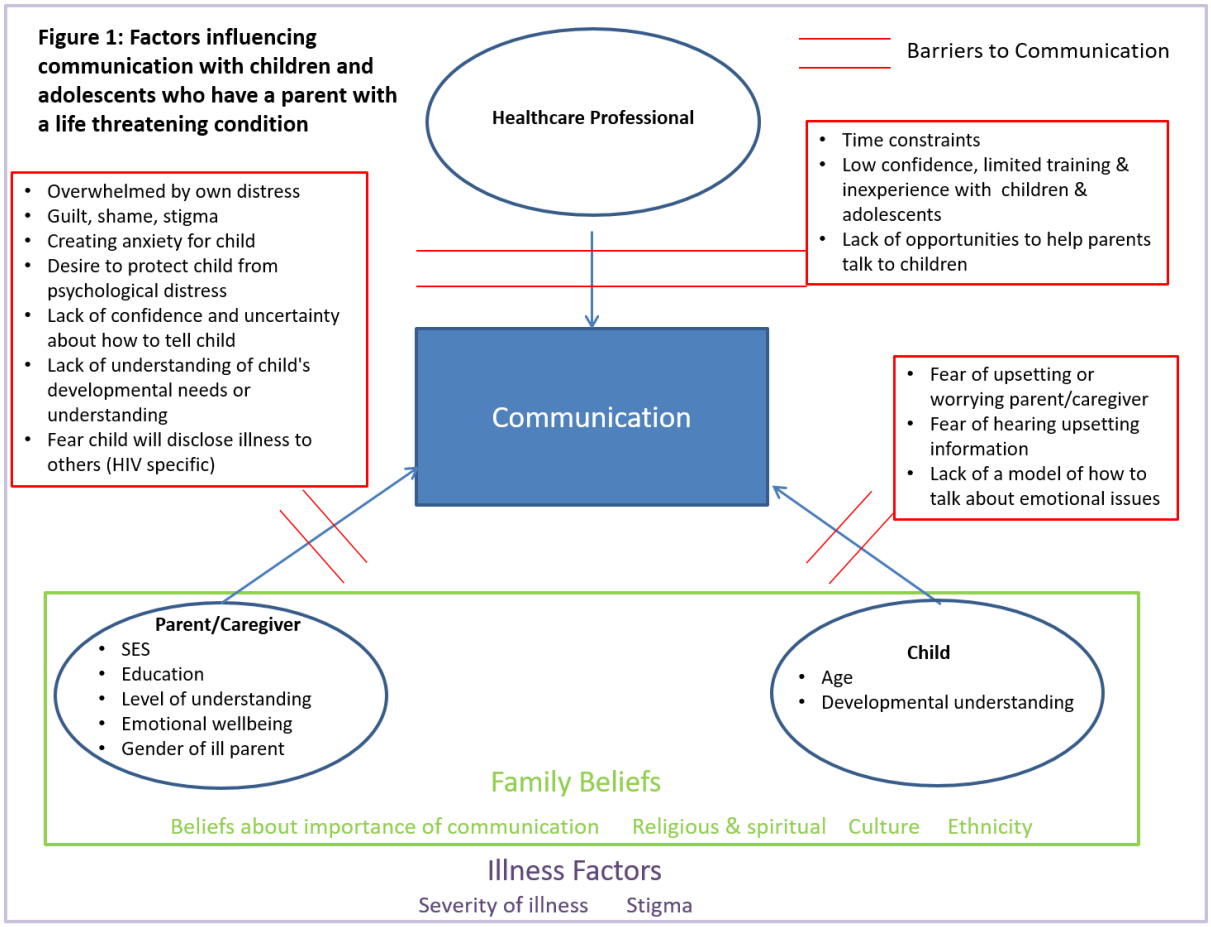
Studies have found that sharing information can encourage trust between children and parents. A UK qualitative study of mothers with breast cancer (n=32) found that some decided to share the diagnosis with their children (n=56; 5-18yrs) in order to maintain trust and facilitate discussion within the family.[45] A qualitative study in Zimbabwe (n=41 adults; n=56 orphans; 7-22yrs) found that secrecy can leave adolescents with feelings of resentment, broken trust and anger.[11] Bereaved adolescents felt that telling the truth "is the best thing" and that they had experienced "hatred" towards the surviving members of the family who had withheld information about their parent's illness.[11]

Some studies indicate potential psychological and physical health benefits for parents following interventions to enhance communication with their children around illness. Evaluation of the uncontrolled Danish study (described above) found an increase in family functioning and a significant decrease in depression for mothers post intervention.[39] An uncontrolled intervention study in South Africa (n=281) designed to facilitate maternal disclosure to HIV-negative children (6-10yrs), found significant improvements in maternal mental health and emotional functioning, although these benefits occurred irrespective of whether the mothers disclosed to their children during the course of the study.[46]

There may also be physical health benefits of communication; mothers with HIV (n=135) in the USA who had not disclosed their status reported sometimes skipping medications because they were afraid their children (6-11yrs) would observe them and then suspect something was wrong.[26] These mothers were also more likely to miss medical appointments than those who had disclosed their status.

3a) What factors influence the process of communication?

Studies have explored factors that might influence communication with children about their parent's condition, including child's age and gender, family sociodemographic factors, parental health and illness beliefs (figure 1).



Age of child

Evidence from studies examining HIV disclosure found that parents are more likely to disclose their status to older children.[10,35,47] Focus groups with HIV-positive mothers (n=60) in India reported that 38% of women suggested it was best to wait until their children (0-10yrs) were older (some reporting this to be at least 15 years old) and able to understand the impact of HIV on the family.[48] A UK study found that child's age predicted when communication about breast cancer occurred between mothers (n=32) and their children (n=56; 5-18yrs), with older children (12 years and over) more likely to be told earlier and given information.[49] These studies also suggest parents may underestimate younger children's awareness of parental illness [13,14] and understanding of illness and death (see child LTC paper). Parental LTCs may pose specific challenges for adolescents; their more advanced cognitive skills may lead them to understand more, and appreciate the potential gravity of their parent's situation.[50] Illness may also complicate the attainment of adolescent developmental tasks of separation and individuation (see child LTC paper).

Sociodemographic characteristics

Some studies have found no relationship between rates of HIV disclosure and ethnicity, marital status, religion, employment status, socioeconomic status, race, mother's age and educational level.[35,47,51] However, disclosure was related to income in a group of African American mothers (n=87; children 6-11yrs) where disclosure was more likely in families with lower incomes.[47] In addition, a South African study found mothers (n=281; children 6-10yrs) with a current partner were more likely to fully disclose their HIV status than those not in a partnership,[52] but this was not replicated in a US study (n=88;

children 5-18yrs).[51] Mothers were also more likely to disclose their HIV status to their daughters rather than their sons,[35,47] and mothers were more likely to disclose their status earlier than fathers.[35]

Severity of parental illness

The decision to communicate parental LTC appeared to be influenced by the severity of the illness, with disclosure more common among parents who were in poorer health.[35,53] A quantitative study of HIV-positive mothers (n=281; children 6-10yrs) in South Africa, found those who considered their health diagnosis as "excellent" were less likely to disclose their diagnosis.[52] Disclosure of HIV can also be related to the severity of physical symptoms, with a higher percentage of disclosure in families where mothers (n=87; 6-11yrs) reported being more "bothered" by physical symptoms.[47] A parent (n=21) becoming very sick was reported as a compelling reason for disclosure to their children (n=24; 5-18yrs) in a qualitative study in Botswana.[10]

In contrast, a Dutch quantitative study (n=212; 11-18yrs) found communication was more open (for daughters) and less problematic (for sons) when parents were undergoing non-intensive (surgical only) treatment for cancer, compared to those on intensive treatment regimens.[31] Daughters also rated communication with the ill parent as significantly more open than that with the unaffected parent, although this could relate to the gender of the ill parent (predominantly mothers in this study).[31]

Parental beliefs around disclosure

Parents expressed varied motivations for disclosing their HIV status including avoiding unexpected shock if the parent dies; making sure the family knew the real cause of their illness (and death); and protecting children from stigma and feelings of hurt if their child learnt the cause from someone else.[54] Some parents hoped disclosing their HIV status to their children would alert them to the risks of becoming infected with HIV through unprotected sex or drug use.[54,55]

Studies have noted the consequences and difficulties parents have experienced by *not* disclosing their HIV status; parents were concerned they would accidentally disclose their status in a moment of stress or high emotion.[53,56] These situations deny the parent time to prepare and/or make the communication process as supportive as possible. In addition, by keeping their HIV status secret the implicit message communicated is that HIV is stigmatising and must be hidden.[35]

3b) What are the barriers and challenges to communication (figure 1)?

Barriers experienced by children

Children's difficulties in communicating about LTCs mirror themes expressed by parents, with children reporting that communication is often impeded by fears of upsetting their parents and a desire to protect their parents by avoiding talking about illness.[17,24] Children (n=7; 11-15yrs) reported finding it difficult to initiate conversations with parents.[57] Difficulties may be related to a sense of guilt and selfishness about burdening parents with their own feelings.[58] Children's avoidance of talking with their parents can in part be due to not wanting to hear upsetting information.[57] Similarly the fear of losing a parent can lead to barriers; in one study sons reported more problems in communicating with parents who had a recurrence of their illness.[31] Children may be aware something is wrong, but feel that they do not actually want to know what it is. A qualitative study in the USA (n=87; 7-11yrs) found

some children experienced a "frightening anticipation" and simultaneous need for denial of their parent's possible death and thus would not communicate with their family.[18] Interestingly, teacher's ratings of child behavioural difficulties were higher than by parental-report, suggesting children (n=80; 8-16yrs) are more likely to manifest their emotional distress at school rather than home.[32]

Barriers experienced by parents

Parents often do not know how to tell their children about their illness[10,24] and want support, ideally from a HCP.[59] Studies indicate that parents do not talk to their child about their illness as they believe their child is too young or unable to understand.[45,54] Parents report feeling unsure about how much information is appropriate,[60] at what age they should talk to their child,[54] or how information should be tailored to their child's age and developmental ability.[24,45] Parents (n=18; children under 18yrs) can lack confidence in how to respond to children's reactions or questions,[59] particularly about death[45] and find it difficult to be honest when the illness has an uncertain course or prognosis.[61]

Parents often fear being overwhelmed by their own distress;[60] guilt about not being able to fulfil their role as parents and grief about missing their child growing up into adulthood.[24] Parents worry about how to manage the reactions of their children in response to the information given and as a result may rely on technical or factual language in an attempt to minimise emotional reactions.[60] Studies both in HICs and LMICs highlight parents' fear of causing their child distress[10,15,34,54,62] creating anxiety,[10,45] or an unnecessary psychological burden.[55,63] Two studies from LMICs also highlighted parental concerns that disclosure of their HIV status would have a negative impact on their child's academic performance at school.[48,63]

Parents with HIV reported specific challenges linked to the sense of shame and stigma sometimes associated with HIV.[10,62] Parents worried that their child would experience discrimination and stigmatisation from others. They feared that children would not keep information about their diagnosis confidential[10,12,48,54] and that disclosure would increase the vulnerability of the family.[26] Parents expressed concern about the potential response of their children to the news of their HIV status, fearing rejection,[55] a loss of respect from their child,[54] discrimination[48] or a refusal to care for them.[63] Potential embarrassment at coping with questions about how the disease was contracted and fear that this might raise broader questions about sexual relationships (which is taboo in some cultures) also contributed to parents' reluctance to talk to their children.[54,55] The relationship between stigma and parental disclosure is inconsistent; parents who perceived their children to be experiencing higher HIV-related stigma were *more* likely to disclose[35] while another study found no such association.[64]

A German study using cancer-registries found that while 66% of cancer survivors (n= 1809) with children (under 22yrs) wanted support about how to tell children about cancer, only 9% accessed such provision.[6565] A systematic review of interventions for families with parental cancer identified 'barriers and facilitators' for engagement with psychosocial support services.[66] This highlighted the perceived importance for parents of interventions that were appropriately structured and targeted, in addition to consideration of practicalities such as childcare that would enable access. Evaluation of a support group for parents (n=21) with recurrent cancer noted that parents had not anticipated positive gains for themselves from attendance, but overcame their reservations if they felt it might benefit their

children (n=30; 4-8yrs).[67] Despite these hesitations, parents reported finding the group a valuable experience, underlining the importance of engaging parents when planning interventions.

Barriers within parent-child relationship

Parent-reported communication may differ from child-reported experiences.[21] Parents may try to conceal and control their own distress in order to protect their children, but in a study of fathers (n=26) and children (n=31; 6-18yrs) who had a mother with breast cancer, children were often acutely aware of their father's emotional state and in turn concealed their own distress to protect their father.[21] Fathers reported that they had "fully reassured" their children about their mother's health, yet children still described remaining worried.

The extent to which parents are able to accurately assess their child's understanding, and consequently tailor communication, has been questioned.[17] When a parent is unwell they are usually the main source of their child's information about the illness and thus the information children receive is filtered by their parents' beliefs, health status, ability to regulate their own emotional state and communication skills.[17] Parents often take on a teacher/educator role, with a focus on sharing factual information.[17] The success of this communication style may be limited if parents do not first check their child's understanding (which may be greater than suspected by parents) or elicit their child's concerns.[13,14]

Although parents often adopted a model of communicating facts rather than emotions, parents wanted their children to share more of their feelings.[17] Interestingly, children reported that their parents were similarly uncommunicative about their own emotions. Parental focus on practical aspects of illness may reflect parental fear about how to manage powerful and upsetting emotional conversations, and how to adequately contain and manage their child's reaction.[17] Parents' concern about revealing the extent of their own distress can create difficulties in communication about emotional issues between parents and children. Children are often aware of how their parents are feeling, but strive to protect them by concealing their own distress.[21,60] Parents may also interpret their child's response in the context of their own preferred coping style; parents who preferred not to talk about their illness perceived their child was coping well when they did not ask questions.[60] Conversely, parents with an open communication style viewed children's questions as a sign of successful coping.

Contextual barriers

HCPs working in adult-focused services may feel inexperienced about talking to children and adolescents about parental illness. They may feel unprepared to facilitate the care patients want and expect in supporting their family throughout the illness and in bereavement.[60] In some LMICs clinics may be a long distance from the family home, providing few opportunities for the HCP to help the parent talk to their children.[68] Often the HCP responsible will have received no, or limited training in helping with communicating about illness (n=35).[69] There are also cultural differences in preparing for death; in some communities around the world talking about death or dying is considered taboo.[70]

4) What are the reported preferences of children, adolescents and parents about the way the diagnosis and information is conveyed?

The research literature identifies themes that are important to children, adolescents and their parents in the content and delivery of communication (Box 1). It is important to acknowledge that the majority of child participants were adolescents with cancer from HICs, but their views offer invaluable and practical guidance for HCPs applicable across multiple healthcare settings. The preferences should be viewed in the context of children's developmental understanding of illness and death (see review of child LTC).

BOX 1: The preferences of children, adolescents and parents/caregivers about the way diagnosis and information is conveyed

Children's preferences about how information is communicated

1. **Information:** children consistently report wanting prompt, clear, simple information about their parent's diagnosis, planned treatment and prognosis.[22,71,72]
    a. Risk of creating anxiety is outweighed by children's desire for information.[17, 73]
    b. Want more information when their parent becomes sicker.[22]
    c. Some children want parents to filter, or "soften", the information according to what they feel able to deal with. This can create tension between conflicting desire for complete honesty and reassurance that everything will be alright.[24]
    d. Paced information so there is time to process content and avoid feeling bombarded or overwhelmed.[22,58]
    e. Specific information about parent's care needs so they can help and be useful.[17,24]
    f. Information about side effects and changes associated with the illness or treatment (such as "grumpiness", appearance post-operatively or hair loss following chemotherapy). Enables children to prepare themselves and reduces feelings of anxiety.[21,22] Ensures that children do not misinterpret normal treatment side effects as deterioration in their parents' health.[58]
    g. Information about range and intensity of emotions experienced by other adolescents in same situation.[22]
2. **Sources of information**
    a. Direct and honest information from parents as early as possible.[73]
    b. Information from parent's clinician
        i. Information from a knowledgeable source.[21,22]
        ii. Ability to obtain information without fear of upsetting parent.[60]
        iii. Visit to clinic can dispel scary fantasies about treatment and "humanise" the doctor.[58] Phone number is helpful even if never used.[22]
        iv. Need HCPs to be proactive as hard to approach them directly.[24]
        v. Children want their own relationship with HCP to be maintained.[74]
3. **Language**: avoid jargon to reduce confusion. Self-referential language should also be used with caution; "they will cut me open" may be more distressing to hear than an objective description using language that disconnects it from the parent-patient[58] (e.g. the doctor is going to do an operation to remove the tumour).
4. **Opportunities for emotion focused communication:** children want opportunities to talk and express their feelings.
    a. Peer support; children often feel isolated from their peer group who have little understanding or knowledge of the challenges facing their family[14,73,75] and want to meet others living through similar experiences in person or online.[75]

b. Use online chat rooms to exchange feelings and experiences (rather than information).[50] May reflect developmental preferences of adolescents, or fear of burdening parents, or feelings of guilt or selfishness about talking about own feelings at home when parent is unwell.[58]
c. Helpful if parents invite adolescents to talk (potentially offering several times); adolescents feel this indicates parents want to hear about their perspective.[58]
d. Unobtrusive support exemplified through allowing "space".[73]

5. Opportunities to ask questions:

a. Discuss worries about causes and heritability of illness; economic impact of illness on family.[21,22,57,72]
b. Option to talk about the possibility of their parent's death[22,71,72] and who will care for them after their parent dies.[72]

Parents' worries about communicating the diagnosis and parents preferences about information and help

Parents describe feeling:

a. Overwhelmed and frightened about sharing diagnosis while managing own emotional reaction.[60]
b. Anxious about "harming children" through not telling them in "right" way or at "right" time.[54,76]
c. Unable to answer potential questions about the source of the illness[77] and concerns about the child maintaining confidentiality of the diagnosis.[78]

These challenges appear to drive parental requests for:

a. Shared responsibility with HCP for child's wellbeing[76]; parents report rapport with HCP facilitated disclosure.[78]
b. Time with clinician to discuss what to say[21,45,54] and what language to use.[56]
c. Guidance about children's understanding of death, appropriate language to use[45] including appropriate leaflets or books with pictures to share. [21,69,74,78]
d. Information about how other families coped, children's normal reactions in order to understand their behaviour.[21]
e. Flexibility about timing of disclosure conversation.[78]

Expert Group Workshop and Development of Framework

The expert group of clinicians and researchers with extensive experience of working with families affected by LTC in HICs and LMICs met for a two day workshop in Oxford, UK in 2017 (see review of child LTC).

In developing these guidelines (box 2), we appreciate that a range of HCPs will be involved in these discussions; in HICs these will more likely be oncologists, family practitioners or infectious disease specialists, while in LMICs, these will be medical officers, nurses or community healthcare workers. Different cultures must be considered, and what is appropriate to discuss with children must be considered, whilst upholding the principles of the UN Convention on the Rights of the Child.[79]

Limitations and Future Directions for Research

The literature is complicated by methodological difficulties; participants have been recruited from a range of sources, most frequently through the parent's hospital oncology or HIV services, but also from charities and voluntary organisations, community adverts[16] or population-based surveys.[15] Most research has also focussed on mothers rather than fathers. Comparison of studies can be

compromised by differences in the stage of parental illness at the time of data collection ranging from newly diagnosed[21] to 10 years since bereavement.[15] Some studies restricted participants to a relatively discrete time frame e.g. 2-5 months since diagnosis[14], whereas others were much more wide-ranging.[31,33] These factors may contribute to a loss of detail and specific needs at particular stages of the disease, or conversely the value of reflection on the whole illness journey, and how communication needs may change over time.

The influence of the socioeconomic and geographical context on treatment availability and prognosis also affects generalisability. Work in LMICs is almost exclusively limited to parents with HIV (rather than other conditions) and the specific stigma associated with HIV may affect the relevance of findings from this group for other LTCs. Only three studies conducted in LMICs (all qualitative) directly involved children as research participants (in contrast to HICs); future research must strive to sensitively include children as active participants. Most studies recruited children over the age of 11 which may limit the applicability of research in younger children, although children as young as 6 have been interviewed.[14] The relatively wide spread of ages within individual studies[14] risks overlooking the specific needs of different age groups and developmental transition points.

The fear of the emotional impact of diagnostic conversations on HCPs, parents and children is the predominant, underlying reason for these not occurring. Similar concerns may also extend to and inhibit the research agenda. Identifying what support is required to overcome these emotional barriers and how this could be sustainably delivered, particularly in contexts where the disease burden is high and resources are limited, is needed. A programme of formal communication skills training is critical, both in medical schools and other healthcare curricula, as well as part of continuing professional development for frontline HCPs. Evaluation of training and how this translates into enhanced clinical practice is essential.[7]

Models of family-centred care (in paediatrics) which acknowledge the impact of a child's illness on all members of the family, have been adopted in many HICs.[80] Given the impact of parental illness on child outcomes, it is timely to consider how a similar model could be of benefit in the management of adult patients and their families. As a minimum, services should provide proactive support and guidance for parents about communicating diagnoses to children. Adult clinicians should take overall responsibility for ensuring parents have support and should discuss with parents whether they would like an appropriately trained HCP to facilitate this directly through a family consultation.

Communication is not a single event, and following diagnostic conversations there remains a need for ongoing communication. Families may be supported by other services or the wider community including charitable and voluntary organisations, although availability varies widely across LMICs and HICs. Building an infrastructure to provide support around family communication requires recognition of the training, time and financial commitment involved. Research generally focuses on communication and the relationship between family members and hospital-based HCPs, at the expense of considering the roles and responsibilities of professionals in the wider healthcare and community system e.g. family/general practitioners, spiritual leaders and school staff. It is essential there is discussion amongst all HCPs involved to decide who will take lead responsibility for addressing the children's communication needs.

Principles to assist health-care professionals communicating with parents and children about parental life-threatening conditions

Principle	Detail	Challenges	Suggested Phrases for Parent	Suggested Phrases for Children
Prepare yourself	Examine your own comfort levels and beliefs. Ensure parents can see a calm and focused person who is emotionally available. Use of supervision/ consultation as well as peer support can be invaluable. Consult relevant disease specific guidelines if available.[1,2]	Time pressures and work load.		
Prepare information	Try and establish if patient has children. Consider what ongoing input you are able to offer parents and children (e.g. availability for direct contact with children). Check you know the names of the parents and names and ages of children. This is important to ensure language and content is developmentally appropriate. Addressing family members by name will make the consultation more personal. Consider how to initiate the conversation about patient's children.	May be difficult to establish if adult patient has children (e.g. in the Accident and Emergency Department). Adult clinicians may feel unskilled or inexperienced talking about children.	"Can you tell me about your family?" "Who lives at home with you?"	
Prepare environment	Consider suitable location (quiet or private) and timing of conversation with parents (both if possible) and children.	Private or quiet space may not be available.	"Let's move to this quieter space so that we can spend some time talking together."	

Explore parents' views about talking to their children	Acknowledge concerns that parents may have about telling their children. If parents express doubt about talking to their children explain that they may have already noticed changes e.g. physical and emotional changes, absences, which lead to children's distress. Suggest it is better to talk to children so they are not alone with their worries, or find out the diagnosis from another source, especially if ongoing treatment and changes in physical state. It may be helpful to discuss their children's developmental understanding of illness[3] Acknowledge emotional aspects of a parent telling their child about their condition and desire to limit child's distress. Explore parental fears or barriers to talking to their children. Problem solve around perceived barriers, whilst respecting parent's role, wishes and beliefs.	Parents may feel reluctant to talk to their children; reassure parents that it is not uncommon to feel this way. It can be helpful to tell parents there is no hurry to decide, that they can give this decision some thought and another meeting can be arranged in a few days time.	"Thinking about talking to your children about this probably feels the hardest thing in the world. It's completely understandable to want to protect them from this news. Are there particular things that make this even harder for you?" "I wonder if your children have noticed that you've been losing weight / been unexpectedly away from home a lot recently?" "We know from experience that sometimes when we don't share things about illness with children, they often realise something important is happening. They have active imaginations and what they imagine can even be worse than the reality."	

			"We know that you know your child inside and out. We appreciate you are the expert in your child and we will always work with you."	
Prepare the parents	Acknowledge and support parent with their own feelings/distress about their diagnosis. Prioritise key information for parents. They may struggle to assimilate information due to fatigue, pain or emotional distress. Encourage parent to ask the child how much they know about the life-threatening condition and pace subsequent information in response to children's emotional reactions and wishes. The conversation may need to take place on several different occasions. Discuss with parent how best to describe the life-threatening condition; suggest simple phrases or narratives the parent could use to explain the life-threatening condition to their children, including the name of their life-threatening condition, what they may observe, and what they should expect. Encourage parent to only convey information that is true and can be elaborated in due course. This is important to maintain the children's trust in their parent/caregiver.	If parents are separated, discuss with parents who will tell the children and the involvement of other biological parent.	"Would you like to sit and talk with me now about how you will tell your children and what words you could use? If you like, we can then practice this together." "I know you are worried that telling your children will be upsetting for them. Yes, it is likely they will be upset or even angry. These are natural emotions and responses to have. Be assured that talking to children is important in helping them through this difficult time." "Younger children may focus much more on the practical aspects of how the life-threatening condition will change	"Today we went to the clinic because Dad hasn't been feeling well. Shall I tell you a bit more about what the doctors told us?" "You know that Mummy hasn't been feeling well and we needed to find out what was wrong. We went to the hospital where the doctors did some special tests to try and find the problem. Today the doctors told us Mummy is ill because she has an illness in her blood called cancer." "The doctors are giving Dad some strong medicine called chemotherapy to try and treat the cancer. We hope this will help

	Suggest to parents they may find it helpful to prepare a script and practice this before talking to their children. Suggest parent may find it helpful to include their partner, a family member or friend in their conversation with the children. Highlight to parent themes from literature about what children report is important in communication about life-threatening conditions. Offer parent resources (e.g. leaflets, story books, web resources) to share with their children. Encourage parent to check children's understanding of what has been communicated and importance of repeating key messages.		their day to day life; who will take me to school? They might not show an immediate reaction to the news (for example wanting to go and play) but this doesn't necessarily mean they didn't hear the news and distress can be shown in other ways."	him get better, but it will also make him feel very tired." "The doctors and nurses are trying very hard to make Mummy better and I really want Mummy's medicines to work but sometimes medicines do not work."
Reassurance for parents that discussion will not cause more problems	Reassure parent it will not cause harm to share some of their emotion with children but openness does not mean sharing full expression of their own grief. Encourage parent to consider how they can/want to 'model' for their children in responding to the life-threatening condition (e.g. sharing emotions, possibly using humour).[4] Labelling emotions (e.g. sad, scared, angry) is useful and allows modelling of emotional sharing and expression.	Alert parent to children's common reactions e.g. sadness, anger, and reassure parent that these are normal responses and does not mean the parent has done the wrong thing, or that the child does not want further information at a later date.	"It's ok to talk with your children about how scary and sad this news is. Sharing your feelings can be helpful, but children may find it frightening to see you completely overwhelmed with distress." "It is useful if you name your emotion, for	"I know that this is sad and scary to think about, but it's better that we share how we are feeling and talk about our worries, rather than having to struggle with it by ourselves"

	Help parent feel confident to reassure their child that they will be loved and looked after no matter what the future holds.		example explain that you are feeling sad and that you are crying because sometimes you feel a bit sad and you feel better after a good cry."	
Common questions	Support parent to nurture children's confidence to initiate conversation and ask question. Anticipate common questions that children may ask. Parents may benefit from rehearsing with you how to answer these questions at a developmentally appropriate level. This also provides an opportunity for you to check parents' own understanding of their condition. Encourage parent to reassure their children that their distress is normal and acceptable. Discuss ways parent can encourage children to ask questions as they arise and review their children's feelings regularly. Discuss with parent the possibility older children may independently seek further information online, which may be of varying factual quality. Encourage parental dialogue with their children about online information.	Questions about the possibility of parental death are disease and stage specific. Answers need to consider child's age and level of understanding.	"Children often want to know what caused the illness and are worried that it might have been their fault." "Children may ask you if you going to die, who will look after them and whether they can catch it. Shall we plan how you might deal with these questions at home?" "Would it be helpful to have a session with you and your children together?" If child asks "Are you going to die?" depending on prognosis one can say "That's a difficult question to	"Would you like to talk to the doctors; you can come with me one of my clinic visits?"

			answer but we do know, from talking to the doctors, that they are going to do everything they can to help me"	
Future thinking	Discuss with parent how they can involve children in day-to-day aspects of the life-threatening condition. Encourage parent to establish a 'new normal' while maintaining boundaries and hobbies where feasible. Encourage the parent to share the practical and emotional burden with the well parent, family and friends. If parents are separated, discuss the benefits of maintaining a consistent message for their children. Identify who else knows about the life-threatening condition and who the child can talk to. Explore the importance of children's teachers and school. Identify ongoing sources of support and community resources (e.g. parent groups, voluntary sector, online forums or websites, written story books and other resources such as http://www.compassionbooks.com/categories/Serious-and-Life%252dThreatening-Illness/?sort=featured&page=2). Discussion may need to include consideration of who will care for the children if the parent is		"If you can, do accept offers of practical help or emotional support from friends and family with whom your children feel comfortable, in order to keep their day to day routine." "Children spend a large amount of time at school and so it is important for the school to understand what your child is going through. School can also be a really helpful source of support for your child. Try to keep the school up to date." "It will be really helpful for your children to have somebody to talk to outside of the family. Being able to share their	"I know it can feel scary when you don't feel sure about what's going to happen. I feel that way sometimes too. What I do know for sure is that I love you very much. We will work through this together as a family, whatever the future holds."

	hospitalised, or for single parents, custody arrangements.		feelings without worrying about upsetting you is really important. ”	

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Authors' contributions

Alan Stein (AS) conceptualized and designed the review. Louise Dalton (LD), Lucy Hanington (LH), and AS undertook the literature searches and selected the studies. AS, LD and Elizabeth Rapa (ER) gathered the information from the studies and drafted the manuscript. Sue Ziebland (SZ), Tamsen Rochat (TR), Aisha Yousafzai (AY), Brenda Kelly (BK) and Ruth Bland (RB) contributed to writing specific sections of the manuscript. Communication Expert Group commented on drafts of the manuscript and contributed to the development of the guidelines. LD and ER compiled the tables. All authors have read and approved the final version of the Review.

Conflict of Interest statements

EH declares she is deputy chair of the NICE clinical guideline development committee for NG61 (End of Life Care in Infants, Children and Young People').

All of the other authors declare no Conflicts of Interest.

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The funder of the study had no role in any aspect of the review.

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Appendix

Methods

1. Literature Review

A narrative approach was adopted to provide a comprehensive overview of the available literature and address the wide ranging research questions outlined above. This inclusive methodology was particularly important given the breadth of available literature, ranging from large scale randomised controlled trials (RCTs) to qualitative studies exploring the detail of patient experiences. The search strategy focused on publications since 2000. However, in the context of evolutionary changes in healthcare philosophy around communication, different rates of change across high income countries (HICs) and LMICs, and gaps in the recent literature, we also included consideration of earlier studies (see Box 1 and Box 2 for search strategy and selection criteria).

2. Expert Group Meeting and Development of Framework

In the context of the available research evidence and limited child-focused, evidence-based guidelines, an interdisciplinary expert group was convened to synthesise the theoretical, academic and clinical experience of the members to develop a framework for communication. The workshop was attended by 16 professionals and an additional 4 members contributed to subsequent discussions, review and framework development to create an expert group (n=20). The group members had experience of working in HICs (Denmark, Sweden, UK, USA) and LMICs (Cameroon, Laos, Mozambique, Myanmar, Pacific Countries of Vanuatu and Fiji, Pakistan, Rwanda, Sierra Leone, South Africa, Tajikistan, Tanzania, Timor-Leste, Uganda) with backgrounds in psychology, psychiatry, paediatrics, oncology, palliative care, global health, child development, child protection, health and human rights, education, anthropology and sociology. The workshops included presentations on the literature review in HICs and LMICs and the academic and clinical work of the assembled group. Although caregivers and children were not direct participants of this workshop, a series of videos presenting parents' perspectives about talking to children about LTCs were reviewed (these have been published as a clinical and training resource at http://healthtalk.org/content/talking-children-about-parents-life-threatening-illness). Following extensive discussion, core principles were derived for use in developing a framework. This was then further refined through consensus to create a basic framework. During this iterative process, information gaps were identified and future research directions discussed. The framework was also reviewed by a parent currently undergoing treatment for cancer. We use the term parent throughout, but note that in some circumstances it may be a caregiver rather than a parent.

BOX 1: Search strategy and selection criteria

Data for this Review were identified using CINHAL (EBSCOHOst)[January 1982- May 2016], Embase (OvidSP)[January 1st 1974- May 11 2016], Medline(OvidSP)[January 1946-May 2016], PsycINFO(OvidSP)[January 1967-April 2016], Science Citation Index & Social Science Citation Index(Web of Science Core Collection)[January 1945- May 2016]. We used a combination of keywords in title/abstract and subject headings for the following key concepts: children, communication and life-threatening illness and we applied a search filter to identify systematic reviews of qualitative studies. Commentary, letters, conference abstracts, dissertations and case reports were excluded. See appendix for search strategy. 5427 records were identified of which 2132 were duplicates. 2281 potentially relevant articles and reviews were reviewed by LH and LD. Our final sample consisted of 43 articles from the search and an additional 34 articles identified from references of relevant articles.

BOX 2: Search strategy used in Medline (OvidSP)[from 1946]. Other strategies are available on request.

# ▲	Searches	Results
1	(child* or schoolchild* or pediatric* or paediatric* or boys or girls or adolescen* or teen* or youth? or young people or young person?).ti.	882902
2	communication/ or information seeking behavior/	69970
3	(nurse-patient relations/ or physician-patient relations/) and (communicat* or talk* or discuss* or disclose? or disclosure).mp.	29711
4	(parent-child relations/ or father-child relations/ or mother-child relations/) and (communicat* or talk* or discuss* or disclose? or disclosure).mp.	9697
5	Truth Disclosure/	12260
6	(communicat* or talk* or discuss* or disclose? or disclosure).ti.	97059
7	((communicat* or talk* or tell* or told or discuss* or disclose? or disclosure) adj3 (truth or diagnos* or prognos* or death or dying or terminal*)).ti,ab.	20672
8	2 or 3 or 4 or 5 or 6 or 7	191951
9	1 and 8	14897
10	((communicat* or talk* or discuss* or disclose? or disclosure) adj3 (child* or schoolchild* or pediatric* or paediatric* or boys or girls or adolescen* or teen* or youth? or young people or young person?)).ti,ab.	12176
11	9 or 10	23230
12	Attitude to Death/	14364
13	exp Terminal Care/ or Terminally Ill/	46221
14	Palliative Care/	44439
15	exp Advance Directives/	6332
16	((lifethreaten* or life threaten* or terminal*) adj2 (ill* or condition?)).ti,ab.	13522
17	(advanced directive? or living will? or "do not resuscitate" or resuscitation order? or assisted suicide?).ti,ab.	5701
18	((place or home or hospice) adj2 (die or dying or death)).ti,ab.	2190
19	((palliative or hospice? or "end of life" or terminal) adj2 (care or therap* or treat*)).ti,ab.	36763

20	*neoplasms/ or exp *breast neoplasms/ or exp *colorectal neoplasms/ or exp *testicular neoplasms/	647765
21	exp *leukemia/ or exp *lymphoma/	275110
22	*Brain Neoplasms/	76640
23	(cancer* or carcinoma? or tumour? or tumor? or malignan* or metasta*).ti.	1562751
24	((breast or testic* or colon* or bowel or colorect* or colo-rect* or brain) adj3 (cancer* or carcinoma? or tumour? or tumor? or malignan* or metasta*)).ti,ab.	445150
25	(leukaemia or leukemia or lymphoma?).ti,ab.	330877
26	*hiv infections/di	7520
27	((hiv or human immunodeficiency virus?) adj3 (disclose? or disclosure or diagnos* or prognos*)).ti,ab.	11046
28	Hemorrhagic Fever, Ebola/	2784
29	ebola.ti,ab.	4794
30	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29	2278846
31	11 and 30	1744
32	limit 31 to "reviews (maximizes specificity)"	23
33	(Qualitative systematic review* or (systematic review and qualitative)).ti,ab.	3131
34	(evidence synthesis or realist synthesis).ti,ab.	2023
35	(Qualitative and synthesis).ti,ab.	4232
36	(meta-synthesis* or meta synthesis* or metasynthesis).ti,ab.	559
37	(meta-ethnograph* or metaethnograph* or meta ethnograph*).ti,ab.	269
38	(meta-study or metastudy or meta study).ti,ab.	65
39	(realist review? or realist synthesis).ti,ab.	199
40	systematic review*.ti,ab. and qualitative research/	416
41	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40	8731
42	31 and 41	4
43	32 or 42	24

Table 1: Studies concerning communication with children about life threatening illness in their parent

Author	Qualitative or Quantitative	Size of study (n)	Type of participants	Child age range in years(mean)	Parental diagnosis	Method of recruitment	Method & measures	How was communication assessed?	Results	Location
Armistead, Tannenbaum et al. 2001[47]	Mixed methods	174	87 HIV-positive mothers; 87 children	6-11	HIV	HIV clinic	Disclosure classed as: disclosed or non-disclosed (maternal rating). Semi structured interviews (child reaction to disclosure). Mothers: PSI, CBCL. Child: CBCL, CDI	Disclosure status	Less than 30% of mothers disclosed to their children. Disclosure more likely in families with lower incomes & mothers who reported being more bothered by physical symptoms. Higher rates of disclosure to girls & to older children. Disclosure unrelated to internalising or externalising problems	USA
Barnes, Kroll et al. 2000[45], Barnes, Kroll et al. 2002[49]	Mixed methods	88	32 mothers; 56 children	5-18	Stage I or II breast cancer	Mother's medical team	Semi structured interviews (timing & extent of communication about diagnosis & treatment, reasons & barriers for communication). Total communication scores calculated based on categorisation of interview responses	Content analysis & total communication scores	Mothers gave their children varying levels of information at different stages of the diagnostic/treatment journey; 70% given information after second outpatient visit when diagnosis confirmed by biopsy. Older children told earlier about parental illness. Children of more educated mothers given less information. Child gender did not effect total communication. Most common reason for not communicating was avoidance of children's questions, particularly about death. Many mothers wanted advice from HCP about how to talk to their children about illness	UK
Beale, Sivesind et al. 2004[13]	Qualitative	28	Children	3-18	Cancer (locally recurrent or metastatic)	Parents' medical team & palliative care service	Semi structured interviews or play based assessment for ages 3-8 (emotional response to parental cancer)	Content analysis	Children with dying parents had greater understanding of their parent's illness than their parents thought. Even small children were aware of parent's medical condition & implications	USA
Bugge, Helseth et al. 2009[76]	Qualitative	13	6 patients; 7 partners & ex partners	5-18	Incurable cancer (breast, bowel, brain,	Part of The Family Support Program	In depth interviews (experiences of family illness and Family Support Program)	Kvale guidelines	Parents concerned about harming their children by not telling them in the 'right' way or at the 'right time'. Parents wanted guidance from, & a shared responsibility for their child's	Norway

					pancreas)				wellbeing, with HCP. Parents needed reassurance & validation about how they had communicated their illness with their children thus far. Separated parents found it helpful to have facilitated conversations in order to support their mutual children. Parents found it helpful to have information about children's normal reactions to such circumstances to understand their child's behaviour. Parents reported the programme helped their children talk more within the family about how they were coping & in voicing the 'difficult questions' which might otherwise be too difficult to raise	
Bylund-Grenklo, Kreicbergs et al. 2015[15]	Quantitative	622	Bereaved child	18-26 (age 13-16 at time of bereavement)	Cancer	Population based survey	Swedish National Causes of Death Register & Multi-generational Register used to identify parents & children respectively. Postal questionnaire developed by study team (awareness of parental death & extent of communication with dying parent)	Questionnaire	98% reported teenage children should be informed when the parent's death was imminent, but only 59% had been informed. Often parent(s) and teenage children pretended that the illness was not that serious to avoid communication	Sweden
Christ and Christ 2006[19]	Qualitative	87	Children	3-11	Cancer	Children of participants enrolled in a parent guidance intervention for families beginning 3-6 months pre bereavement & 14 months after parental death	Individual interviews 6 months before death anticipated, at time of parent's death, and during immediate post-bereavement period. Interviews (experience of parental illness, death & bereavement)	Content analysis	3-5 year olds observe physical manifestation of parent's illness but cannot understand permanence of death. Children need a concrete description of what death means & caregivers should anticipate children's' questions will be frequent & repetitive. Authors recommend parents ensure that children are adequately supported when visiting sick parent; uncontained parental grief & distress can be frightening for children.	USA

									6-8 year olds need simple, concrete information & simple explanations about parent's behaviour, appearance, symptoms & treatment to avoid magical thinking. Children may have variable awareness of parent's imminent death & are sensitive to emotional state of parents & react accordingly. 9-11 year olds can use logical thinking to understand cause & effect, but still require concrete explanations & sequenced information	
Christ, Siegel et al. 1993[18]	Qualitative	87	Children	7-11	Advanced/terminal cancer with expected survival time of 6 months	Cancer Centre	Individual interviews (experience of parental illness & death) with children before parent had died	Content analysis	Common fears & concerns; impact of illness & side effects on children, fear of parent's death. Children's developmental understanding of illness & death can lead to misunderstandings of the cause of illness & visible symptoms in the absence of concrete information from parents	USA
Chowns 2013[73]	Qualitative	9	Children	7-15	Cancer	Social worker in palliative care team	Participant researched their own lived experiences by making a group DVD	Content analysis	Adolescents' experience a sense of isolation, uncertainty about the future & need support in facing the anticipated difficulties ahead, rather than protection from them. They want the truth about their parent's condition & comprehensive, timely information	UK
Davey, Tubbs et al. 2011[75]	Qualitative	12	Children	11-18	Breast cancer	Parents' medical team	Three focus groups with semi-structured discussion format (experience of parental diagnosis, treatment, relationship & emotional response)	Content analysis	Children found it hard to share feelings with friends who had not experienced parental cancer. Described feeling overlooked & unappreciated by their parent's medical team. Keenly aware of their parents' treatment regimen & side effects. Wanted a teen group around the time of diagnosis & treatment. Preference to talk to young people, but acknowledged some incentive might be necessary to encourage them to attend the group initially.	USA

De Baets, Sifovo et al. 2008[63]	Quantitative	195	64 HCPs; 131 community members	0-12	Community sample considering factors influencing HIV disclosure in hypothetical scenarios	Primary healthcare centres (not specifically parents')	Disclosure classed as: Full disclosure (to have all information); Partial disclosure (being told there is a disease, but not specifically HIV); No disclosure (being told nothing) 32 item questionnaire (related to disclosure) developed by researchers plus 7 questions specific for HCP about their confidence in assisting with disclosure	Descriptive analysis	For a hypothetical situation, 63% of participants expressed the need to give a child some information about the parent's HIV status, with 69% opting for full disclosure to children older than 11 years. HCPs opted for partial & full disclosure at significantly younger ages than community members. Higher levels of education associated with full disclosure at a significantly younger age. Up to a third would prefer to initiate conversations about HIV disclosure & grief with own children without assistance. However over half would prefer to have involvement from a health worker & 40-50% have help from a family member (most commonly father's sister & grandmother, rather than partner)	Zimbabwe
Edwards, Watson et al. 2008[28]	Quantitative	109	56 adolescents ; 53 mothers	11-17	Stage I/II breast cancer	Single cancer centre	Adolescent: YSR of CBCL, CHQ-MH, C-IES, FAD, FES. Mothers: BDI, SF8 version of Medical Outcomes Health Survey	FAD	Poor family functioning & cohesiveness associated with adolescent emotional & behavioural problems. Poor family cohesiveness associated with increased stress responses. Internalising & externalising behaviour significantly associated with poor communication & poor affective responses	UK
Ellis, Dowrick et al. 2013[16]	Qualitative	33	Adults who had experienced the death of a parent before the age of 18	13m-17yrs at time of death 20-80 at time of study	Mixed group including cancer, heart attack, stroke & trauma	Community recruitment through media	Participant chose to write their experience or take part in an in depth narrative interviews (impact of parental death)	Narrative analysis	Distress compounded when children not given accurate information. Some described "implicit rules" for not speaking about the deceased parent had a negative impact on family functioning	UK
Ernst, Beierlein et al. 2013[65]	Quantitative	1809	Adult patients diagnosed no more than 6 yrs	<22	Cancer	Cancer registries	HADS, OSSS, FAD,SF-8, Likert scales regarding use of psychosocial support	Not measured	73% of cancer patients with children wanted either information (about how to talk to their child about cancer, common emotional responses of children to such news) or active psychosocial support regarding issues pertaining to parental cancer. 9% of	German

									participants had accessed family or child-centred support; rates of satisfaction with this input were high.	
Forrest, Plumb et al. 2006[14]	Qualitative	68	37 mothers; 31 children	6-18	New diagnosis of stage I-IIIa breast cancer	Single cancer centre	Individual semi structured interviews (child awareness, understanding, reaction to diagnosis & treatment, informational needs)	Thematic analysis	Even the youngest children were aware of cancer as a life threatening illness. Children suspected something was wrong before they were told the diagnosis. Parents sometimes misunderstood their children's reactions & underestimated the emotional impact of the illness. Parents did not always recognise the child's need for preparation & age appropriate information about the illness, treatment & side effects	UK
Forrest, Plumb et al. 2009[21]	Qualitative	57	26 non-affected fathers; 31 children	6-18	Maternal new diagnosis of stage I-IIIa breast cancer. Child interviews 3-6 months after diagnosis	Single cancer centre	Individual semi structured interviews (child awareness, understanding, reaction to diagnosis & treatment, informational needs). Child interviews sometimes included drawing & play	Thematic analysis	Fathers wanted to protect & reassure their children but felt this was hindered by insufficient information about breast cancer. Fathers did not always recognise the extent of their child's distress or misinterpreted signs of distress. Children were aware of their fathers' distress & wanted to protect him.	UK
Giesbers, de Leeuw et al. 2010[50]	Qualitative	137	129 children; 8 adults	8-46 (15.3, median 14)	Cancer	Users of website for children of parents with cancer	Analysis of forum discussions on Dutch website (www.kankerspoken.nl) over a 3 month time period	Content analysis	Young people used website to share personal experiences, provide encouragement/support or seek information & advice. Children regularly faced emotional problems & experienced a lack of understanding & communication in their direct environment	Netherlands
Harris and Zakowski 2003[27]	Quantitative	50	Adolescents	12-19 (15.7)	Cancer diagnosed within last 5 years	Cancer support groups & oncology clinics in three US states	Telephone completion of CDI, RCMAS, IES, PTSD Checklist-civilian version, FES, PRS	FES	No significant differences between groups in symptoms of depression or anxiety. Positive family relationships associated with lower anxiety & depression symptoms in adolescents of parents with cancer. Analysis for both adolescent groups found expressiveness is mediator between family cohesion & anxiety.	USA

Harris 1991[25]	Mixed methods	11	Bereaved adolescents	13-18	Terminal illness, suicide or sudden & unexpected (medical emergency related to underlying condition)	Community resources (most via school counsellors responding to project announcements)	Adolescent followed through the year following parental death using semi structured interviews, DISC (experience of parental death, relationship with deceased, emotional response). Parent interviews. Adolescent: CDI, YSR, IES. Teacher: CBCL. Parent: IES, BDI. Completed at recruitment, 7 & 13 months after bereavement	Descriptive analysis	For some participants the cause of death remained unclear as information given had been insufficient or distorted. These misunderstandings led to feelings of regret & guilt about their possible role in causing or being unable to prevent the death. Most adolescents believed that emotional expression or discussions of death were unacceptable or potentially overwhelming for their friends	USA
Helseth and Ulfsaet 2005[59]	Qualitative	18	Parents (patients & partners)	4 months – 17 yrs	Cancer: breast, colorectal, melanoma, lymphoma	Parent's medical team	Individual in depth interviews (children's reactions & needs, parental experiences & needs) with ill & healthy parent on 2 occasions	Kvale guidelines	Parents reported best way to manage illness was to be open about situation. Parents expressed strong desire for advice about how to talk to their children about illness & felt this type of support was absent. Talking about the possibility of death was a particular area of concern for parents	Norway
Huizinga, Visser et al. 2005[30]	Quantitative	284	Children & adolescents	11-18 & 19-23	Cancer diagnosed 1-5 years prior to study (breast, gynaecological, skin, haematological malignancies)	Single cancer centre	Dutch IES, Dutch YSR, STAI-CH	Not measured	21% of sons & 35% of daughters reported clinically elevated stress response symptoms (IES). Daughters, particularly those whose mothers were ill, reported significantly more intrusion & avoidance symptoms compared to sons. Daughters worry more about their own chances of getting cancer (2/3 of patients in study had female-specific cancer). Perceptions of seriousness of disease related to stress response for daughters, but not for sons	Netherlands

Huizinga, Visser et al. 2005[31]	Quantitative	212	Children & adolescents	11-18	Cancer diagnosed 1-5 years prior to study (breast, gynaecological, skin, haematological malignancies)	Single cancer centre	Dutch IES, PACS	PACS	Adolescents communicated less openly with mothers who had cancer, relative to population reference group data. Problem communication (with both parents) was related to PTSS in sons & daughters. Parents receiving more intensive treatment associated with more problem communication for sons & less open communication for daughters	Netherlands
Kennedy and Lloyd-Williams 2009[24]	Qualitative	28	11 children; 10 ill parents; 7 carers	7-18	Advanced cancer	Parents' cancer centre, oncology team, hospice or GP	Semi structured interviews (to identify communication & informational needs of children when parent has cancer). Children chose to be interviewed alone or with parents/siblings	Constructionist grounded theory approach	All children wanted honest information about their parent's health & treatment; variation with some wanting total honesty & others wanting parents to filter the information according to what they felt able to deal with. Wanted information from a range of sources, including parents, HCP, books, leaflets & online. Concerns about not wanting to upset parents by asking direct questions, lack of access to professionals & age appropriate information. Parents identified informing children of their diagnosis & coping with their children's questions as main challenge. Parents did not want to keep secrets & wanted to prepare their children. Reasons for not telling; causing their child distress or not knowing how to tell them	UK
Kristjanson, Chalmers et al. 2004[22]	Qualitative	31	Adolescents	12-20 (age at diagnosis <12-18)	Breast cancer; recently diagnosed, stages 1-4, remission & terminal	Purposeful sampling. Cancer centre, palliative care programme, hospital-based support group for	Individual semi structured interviews (experience of parental illness, perception of support & helpful information) communication	Constant comparison techniques & FAD	Most salient information adolescents wanted was whether their mother was going to survive. Wanted information about the seriousness of the illness, potential side effects, medical facts, how to help their mother, normal feelings for mothers & young people. Emphasised importance of individually tailored information. Benefitted from time	Canada

						children whose parents had cancer	subscale of FAD. Two focus groups		with HCP to provide facts & follow up information, but difficult to access. Information conveyed in private judged easier to understand. Family members sometimes helpful as information interpreters but adolescents felt their parent's management of information could be too controlling & protective	
Lee and Rotheram-Borus 2002[35]	Quantitative	696	301 parents; 395 adolescents	11-18	HIV	HIV social welfare services	5 year longitudinal study. Disclosure classed as: not having occurred (0), if parents told nothing, that they were ill, or chronically ill; or as having occurred (1), if parents disclosed an HIV or AIDS diagnosis, or that they were dying. Parent: BSI, RSES, family stressors & life events, social support, coping styles, perceived stigma. Adolescent: RSES, BSI, PBI	Disclosure status	Disclosure more likely to older children. Mothers disclosed earlier than fathers & more often to daughters than to sons. Disclosure more common among parents with poorer health, larger social networks & those who perceived child experiencing more HIV-related stigma. Following disclosure, adolescents report more problem behaviours in negative family events. Parents perceive their children experience HIV-related stigma following disclosure	USA
Letteney and LaPorte 2004[51]	Quantitative	88	Mothers	5-18	HIV	HIV Outpatient clinic	Disclosure classed as: 1 = I have disclosed my HIV status to at least one of my children; 2 = I am in the process of disclosing my HIV status; 3 = I have not disclosed my HIV status. PSS, DDM	Disclosure status	No differences in physical or psychological distress between disclosure groups. No differences in marital status, race, religion & employment between mothers who had & had not disclosed HIV status. Mothers who disclosed HIV status had fewer perceptions of HIV-related stigma, more social support & managed HIV-related stigma with strategies other than concealment. Mothers who had not disclosed more likely to feel devalued & discriminated against as result of HIV-	USA

									positive status & to use secrecy to manage perceived stigma	
Maynard, Patterson et al. 2013[58]	Qualitative	15	Young people	14-18 (15.9)	Non terminal cancer diagnosed within last 5 years (breast, mouth & throat, leukaemia, brain & stomach)	Charity or Voluntary organisation	Semi structured interviews (experience of parental diagnosis, emotional needs, parental support & understanding of their experience)	Phenomenological thematic data analysis	Children gauged how much they should worry on their parents' behaviour & used parents as role models for what behaviour was appropriate (e.g. using humour). Wanted parents to be available to talk & answer questions about the diagnosis, treatment & how they were coping. Felt guilty about talking to parents about their feelings, but being invited to talk by parents alleviated guilt. Wanted measured information so not overwhelming. Considerable variation in preferences for level of detail & volume of information	Australia
Murphy, Steers et al. 2001[26]	Quantitative	270	135 mothers; 135 children	6-11 (8.47)	HIV	HIV clinics	Disclosure classed as: (a) nondisclosure (mothers whose children knew nothing of their illness or serostatus); (b) maternal disclosure (mothers who had told their children personally about their serostatus); (c) other disclosure (children who knew that their mothers were ill or chronically ill and children who knew that their mother had HIV/AIDS but were informed by someone other than the mother). Semi structured interviews.	Disclosure status	Maternal disclosure rate of 30%. Reasons for non-disclosure; child too young to understand, concern child would disclose to others, not knowing how to disclose, concern child would respond negatively to disclosure or lose respect for parent. Mothers who had disclosed status reported higher levels of social support relative to those who had not disclosed. Children of mothers who had disclosed had lower levels of aggressiveness & negative self-esteem relative to the non-disclosure group	USA

							Mother: HDI, Family Functioning (2 subscales), ASSIS, CBCL. Child: CDI, HSC, RCMAS			
Murphy, Roberts et al. 2003[56]	Qualitative	47	Mothers who had disclosed to their children	6-11	HIV	Participants enrolled in PACT (Parents and children Coping Together) study	Individual semi structured interviews (process of disclosure & reflections)	Grounded theory approach	Majority of mothers did not regret disclosure to their children. One third of mothers regretted disclosure; regrets categorised into 5 themes: lack of preparation (in terms of timing or planning what to say or when to disclose), timing of disclosure (in relation to child's age, maternal health & concurrent psychosocial stressors), context of disclosure (pertaining to maternal mood), content of disclosure, impact of disclosure on child & desire for professional support for their child	USA
Nam, Fielding et al. 2009[10]	Qualitative	61	21 parents on ART; 40 children (subset of 24 analysed)	5-18	HIV	Infectious Diseases Care Centre (IDCC) & GP practice	Disclosure criteria not reported. Individual semi structured interviews (disclosure, understanding of illness & treatment)	Disclosure status & grounded theory approach	29% of children had been told about their parents' HIV-positive status; 33% thought to have guessed & 38% believed to be unaware of their parents'. Reasons for disclosure: the child being HIV-positive, rest of the family knowing or the parent becoming very sick. Reasons for not disclosing: believing the child to be too young, not knowing how to address the issue of HIV, or that it would be too painful for the child. Parents concerned other people might find out their status or that child would be stigmatised. Parents described difficulties in addressing issues of HIV & sexual health with their children, preference to leave these topics for schools to address	Botswana
Nelson and While 2002[32]	Mixed methods	224	144 parents (80 patients, 64 spouses); 80 children	8-16	Breast cancer, leukaemia, gynaecological &	Cancer centres	Individual semi structured interviews. Child: RCMAS, Adapted SPQ. Self-Perception Profile for Children,	Communication subscale on SPQ, maternal completion of communication measure,	Family relationships not associated with children's adjustment. Two main risk factors for poor adjustment in children were low self-esteem & poor adjustment in parent with cancer. Communication about illness not	UK

					testicular cancer		Social Support Scale for Children. Parent: Rutter Scale A, HADS, MAC, Malaise Inventory, FES, adapted 8-item communication measure. Teacher: Rutter Scale B.	content analysis.	associated with child adjustment so not regarded as risk factor in this study	
Niemela, Paananen et al. 2012[5]	Quantitative	60,069	Children in Finland born in 1987	Retrospective 21 year review of children who had a parent suffering from cancer	Cancer	Data from Finnish Hospital Discharge Register	Use of inpatient & outpatient psychiatric services recorded on Finnish hospital Discharge Register	Not measured	6.6% of children born in Finland in 1987 had been affected by parental cancer before the age of 21 years old. These children, especially females, had used psychiatric services in either in or outpatient settings significantly more often than their peers during follow up time period. Increased likelihood of psychiatric inpatient care observed for male cohort members when their father had cancer	Finland
Ostrom, Serovich et al. 2006[64]	Mixed methods	45	Mothers	5-18 (12.4)	HIV	Longitudinal study; HIV clinics & service organisations	Disclosure classed as: disclosed or non-disclosed (maternal rating). Disclosure measured with a social network screening questionnaire (adapted ASSIS). Reasons for disclosure measured using Likert scales. HIV Stigma Scale	Disclosure status	95% of women did not regret disclosure, wanted to take a lead role in disclosure to their child & make decision based on child's ability to cope with information. Reasons endorsed for disclosure: wanting child to hear diagnosis from mother, child had a right to know, wanting child to understand mother's illness & preparing child for what might happen. Reasons for non-disclosure: wanting child to have a carefree, worry-free childhood, wanting to avoid child's anxiety about mother & protect child from reactions of others. Mothers who experienced stigma reported not disclosing to thei r children for fear of child telling others	USA
Palin, Armistead et al. 2009[34]	Quantitative	103	Mothers	11-16	HIV	AIDS organisations, hospital, radio	Disclosure classed as: disclosed or non-disclosed (maternal rating). Individual	Disclosure status	44% of mothers had disclosed to their child; of these mothers half had disclosed within one year of diagnosis & 70% within 2 years of diagnosis.	South Africa

						broadcasting & word of mouth	interviews (child response to disclosure, disclosure decisions), HESSI, PSI, IBQ PCS, CBCL		Mothers most commonly endorsed their child's reaction to disclosure as sadness & worry. Disclosure to children significantly predicated externalising but not internalising behaviours, with more externalising behaviour in the group who had been disclosed to	
Paliokosta, Diareme et al. 2009[33]	Quantitative	1 57	101 parents; 56 children	4-17	Multiple Sclerosis (duration 2 months-21 years; mean 10.3 years)	Hospital neurology clinics	Disclosure classed as: 1 no information at all; 2 partial information; 3 total disclosure. Individual semi structured interviews. Parent: CBCL, BDI, FAD. Child: YSR, FAD. Functional impairment of patient assessed by doctor using Karnofsky performance Status Scale	Disclosure status	Fathers (both healthy & affected) with higher levels of depression had children who had had more information about parental illness. Parental functional impairment was not associated with communication around illness. Children & adolescents who had 'partial information' had higher scores in social difficulties & internalising behaviours relative to the other two groups. Children's self-rated scores of social problems were significantly higher for those who had had partial information about the parental illness. No correlations between communication around illness & family functioning as assessed by FAD. No relationship between communication & level of parental education	Greece
Phillips and Lewis 2015[57]	Qualitative	7	Children	11-15 (13.6)	Stage IV cancer (breast, colorectal, carcinoid)	Parents' medical team	Individual semi structured interviews (experience of parental cancer, emotional and informational needs)	Inductive content analysis	Individual variation in how much & how often wanted to talk about parent's cancer. Difficult to initiate these conversations & sometimes avoided the topic because it was scary. Others found it helpful to talk about cancer with parents	USA
Rosenheim and Reicher 1985[29]	Quantitative	44	Children	6-16	Cancer (to extent that daily functioning was impaired &	Single cancer centre	Parental report of disclosure classed as: informed (explicit naming of cancer) or uninformed. Child: 54 item Anxiety scale for	Disclosure status	Anxiety of the informed group significantly lower than the uninformed group.	Israel

					evident they were ill; Parents undergoing radio or chemo therapy)		children based on McCandles Costaneda & Palermo (1956)			
Sheehan, Draucker et al. 2014[71]	Qualitative	56	26 adolescents; 10 ill parents; 20 well parents	12-18 (15)	Cancer-17 ALS-1 Multiple Sclerosis-1 Pulmonary disease-1 vCJD-1 No response-1	Parents' medical team at single hospice	Individual interviews (experience of disclosure)	Constant comparison methods	Outcomes of measured telling were always good; parents proud of how they had disclosed their illness/ imminent death & adolescents satisfied at how disclosure occurred. Participants reported it had engendered trust within the family. Outcomes of skirted telling were generally positive; both parents & adolescents welcomed this approach & did not experience discord. Outcomes of matter of fact telling were neutral; not seen positive or negative, rather that these conversations 'occurred'. Outcomes of inconsistent telling were generally negative; adolescents expressed anger & felt they had received too much or not enough information. Parents were aware of their adolescent's dissatisfaction	USA
Sipsma, Eloff et al. 2013[36]	Quantitative	1018	395 HIV positive mothers; 114 HIV negative mothers; 509 children	6-10	HIV	Health clinics	Disclosure classed as: No disclosure; partial; full disclosure. Parent: VABS, CBCL. Child: CDI, RCMAS, BEQI	Disclosure status	7.4% of children had been informed of their mother's HIV positive status & 4.6% partial disclosure. Children of HIV positive mothers who had been told their mother was sick had less internalising & externalising behaviours & improved skills of daily living, compared to children who had been told nothing. No psychological benefit for those explicitly told about HIV compared to the non-disclosure group. Disease severity did not moderate the effect of disclosure on child outcomes. No differences on child reported outcomes	South Africa

Thastum, Johansen et al. 2008[17]	Qualitative	36	21 children; 15 parents	8-15 (11)	Cancer (breast, lung, lymph, cervical) disease duration 2-153 months	Parents' hospital-based medical team, GP & community recruitment (patient organisations, newspaper advert)	Individual semi structured interviews (child knowledge of parental illness & emotional experience; parental report of child's knowledge)	Phenomenological analysis	Children felt important to have knowledge about parent's illness. Generally positive in their reports of visiting hospital although some found it frightening or boring. Parents who had not immediately told their children the diagnosis (to protect their child or because of their own feelings) regretted this decision as they felt their child had reacted negatively to the lack of information	Denmark
Thomas, Nyamathi et al. 2009[48]	Qualitative	60	Mothers	0-10	HIV/AIDS	STD clinics, HIV clinic & 2 maternity hospitals	Disclosure criteria not reported. 9 focus groups using semi structured interview guide based on Comprehensive Health Seeking & Coping paradigm (issues relating to disclosure to child or family)	Content analysis	Mothers feared disclosure; child may discriminate against them, child's studies adversely affected, or child disclosed details to others. 38% of women felt it best to delay disclosure until children older & able to understand the impact of HIV on the family. Suggestions that counsellor or doctor could make or assist in disclosure	India
Vallerand, Hough et al. 2005[53]	Qualitative	54	35 HIV-positive mothers who had disclosed to their children; 19 children	10-18	HIV	Longitudinal study Living with HIV/AIDS: Mother-child Coping & Adjustment	Individual semi structured interviews (issues related to diagnosis disclosure & child experience of disclosure)	Constant comparative method	Disclosure encouraged open, honest communication & closer relationships between mothers & children. Mothers disclosed when they felt their child was developmentally ready, that the information would help protect their child from infection themselves (through unprotected sex) or when their health declined. Reasons for not disclosing: fear of the child not understanding & fear of stigma. Mothers identified some negative effects of disclosure: child's emotional reaction, fears & uncertainty. Mothers & children also raised fears about social ostracisation following disclosure & a need to maintain secrecy around diagnosis	USA
Withell 2009[23]	Qualitative	10	Bereaved adolescents	13-19	HIV/AIDS	Faith-based HIV/AIDS NGO	Unstructured interviews	Descriptive phenomenological approach	Process of moving from a concealed or disguised reality (no awareness parent was seriously ill; awareness of	Uganda

									illness but believed to be treatable) into discerned reality (guess parent dying through observation or intuition), with (for a few) a last minute disclosed reality (disclosure by dying parent). Where information was lacking, children had to construct their own reality of what was really happening to their parent e.g. attributing their parent's death to witchcraft	
Wood, Chase et al. 2006[11]	Qualitative	97	56 orphans; 41 adults (including parents & members of wider community)	7-22	HIV	6 NGO sites	Disclosure criteria not reported. Individual interviews (experience of illness & bereavement) & observations, participatory tools including drawings with younger children	Content analysis	Disclosure to children was rare, although adolescents often strongly suspected their parent's symptoms were HIV-related. Orphaned adolescents wanted direct communication with adults about illness & described negative emotional consequences of secrecy. Adults largely mis-interpreted children's withdrawal & quietness as a positive coping strategy	Zimbab we
Xu, Yan et al. 2007[62]	Qualitative	37	16 caregivers; 5 key informants; 16 children	8-17 (13)	HIV/AIDS (mean time since diagnosis for non-orphans 15 months)	Local community HCPs working with people with HIV	Disclosure criteria not reported. Individual semi structured interviews	Constant comparative method	3 of the 16 children knew their parents had HIV; disclosure prompted by the child seeing some evidence of parental illness. Most caregivers & community informants suggested not telling children to protect them from unpleasant events including discrimination or stigmatisation & psychological distress.	China
Zhao, Li et al. 2015[9]	Quantitative	626	Children	6-17 (10.59)	HIV	Community recruitment	Disclosure classed as: disclosed (told by parents about illness in general or HIV specifically) or nondisclosed. children. Survey (awareness of parental illness & disclosure). CES-DC, CLS, PSS, RSES, SACAA,	Disclosure status & content analysis	31% of fathers & 39% of mothers had told their children about their illness. 95% of children who had not been disclosed to by parents were aware of their parent's HIV status from other people or from their own observations.	China

							Enacted stigma, Children Future Expectation Scale, Hopefulness about future, Perceived control over the future			
Zhou, Zhang et al. 2013[55]	Qualitative	39	Parents	24% <8 years; 24% 8-14 years. 20% 15-21 years; 28% > 21 years.	HIV	HIV clinics	Disclosure classed as: disclosure and non-disclosure. Open ended interviews (reasons for disclosure, impact of disclosure on child, future disclosure intentions)	Content analysis	77% of parents had not disclosed HIV status to children. Parents who disclosed were older & more likely to disclose to their adult children (mean age of children who had been disclosed to was 27 years, range 11-52 years). Reasons for disclosure: need for emotional & financial support, to prevent their child becoming infected, in response to their child's suspicions. Reasons for non-disclosure: child too young to understand, fear of being stigmatised, fear of being rejected by child, fear of psychological burden to child. 50% of non-disclosing participants did not plan to disclose in the future.	China

ASSIS - Arizona Social Support Interview Schedule
BDI - Beck Depression Inventory
BEQI - Baron Emotional Quotient Inventory (Youth version)
BSI – Brief Symptom Inventory
CBCL – Child Behaviour Checklist
CDI - Children Depression Inventory
CES-DC - Center for Epidemiological Studies Depression Scale for Children
CHQ-MH – Mental health subscale of the Child Health Questionnaire
CLS - Children's Loneliness Scale
DDM - Devaluation-Discrimination Measure
DISC: Diagnostic Interview Schedule for Children
ED – Emergency Department
FAD - Family Assessment Device
FPRQ - Family Peer Relations Questionnaire
FES - Family Environment Scale
GHQ - General Health Questionnaire

HADS: Hospital Anxiety and Depression Scale
HCP – Health Care Professional
HDI – Hamilton Depression inventory
HESSI - Household Economic & Social Status index
HIV SS – HIV Stigma scale
HSC – Hopelessness scale for Children
IBQ - Interaction Behaviour Questionnaire
ICU-intensive Care unit
(C)-IES – (Child) Impact of Events Scale
IPA – Interpretative Phenomenological Analysis
MAC: Mental Adjustment to Cancer scale
MASC: Multidimensional Anxiety Scale
MOHS - Medical Outcomes Health Survey (SF8)
OSSS – Oslo Social Support Scale
PACS - Parent-Adolescent Communication Scale
PBI - Parental Bonding Instrument
PCS - Parenting Convergence Scale
POMS – Profile of Mood States
PPI: Parent Perception Inventory
PRS - Perceived Risk Scale
PSI – Physical Symptoms Inventory
PSS - Perceived Stigma Scale
PTSS - posttraumatic stress symptoms
RCMAS- Revised Children's Manifest Anxiety Scale
RSES – Rosenberg Self Esteem Scale
SMFQ-short: Short Mood & Feelings Questionnaire
SMS – HIV-related Stigma Management Scale
SPQ - Sibling Perception Questionnaire
SACAA - Stigma Against Children Affected by AIDS
STAI-CH - State Trait Anxiety for Children
VABS – Vinel & Adaptive Behaviour Scales
YSR- Youth self-report form

Table 2: Studies evaluating clinical interventions for families when a parent has a life threatening condition

Author	Size of study (n)	Type of participants	Child age range in years (mean)	Parental diagnosis	Method of recruitment	Method	Description of intervention	Measures	How was communication addressed during intervention?	Results	Location
Betancourt, Ng et al. 2017[43]; Chaudhury, Kirk et al. 2016[44]	293	170 children; 123 caregivers	7-17 (11.76)	HIV	Parent's medical team	RCT	Modular, home-based (Family Support Intervention, FSI) to promote parent-child relationships. Aim: to elicit participants' current challenges & apply family's strengths & strategies successfully used in past. Control group: treatment as usual	Adapted & validated for Rwandan context. Child: CES-DC; conduct problems scale; WHODAS-Child, Family Connectedness, Parenting scale adapted from PARQ. Parent: Family Connectedness, parenting scale adapted from PARQ	Intervention aimed to improve communication & understanding	Children who received FSI had fewer symptoms of depression (parental & self-report) at 3 month follow up. No differences between groups on outcomes of child behaviour, child functional impairment, family connectedness or parenting. After HIV disclosure children reported lower levels of parenting & family unity scores; these differences were not seen at 3 month follow up	Rwanda
Christ, Raveis et al. 2005[40]	184 (plus a comparison group of 556 non bereaved children)	184 families	7-17	Cancer; advanced disease with estimated survival time of 6 months or less	Parent's medical team	RCT	12 month parent-guidance intervention of 6 or more sessions; psychoeducational; enhancing surviving parent's ability to provide care & support for children; provide environment where child felt able to express feelings about loss & maintain consistency & stability in child's environment. Support for parents through their own grief work in order to enhance their capacity to function effectively. Individual interview of child; perceptions of family communication which then informed parent intervention. Control group: telephone monitoring 4-8 weekly; maintain contact with well parent & facilitate referral to appropriate resources. Initiated during parent's	Child: CDI; STAI-ch; PPM; IDRCM. Parent: CBCL	Current approaches to communication within family & terminal illness discussed Often included encouraging extensive preparation of children for progression of illness, reviewing specific words & concepts for talking about illness, treatment & death, developmental issues & impact of parental feelings on their ability to understand or meet child' needs	No statistically significant differences between groups on measures of child anxiety or depression, but children of parents in experimental arm a greater decline in scores over time (from initiation of intervention to 6 months post bereavement). Children of parents in experimental arm rated their parent's overall competence & general communication as significantly better during & after the intervention compared to control	USA

							terminal cancer & continuing until 6 months after death				
Greening 1992[67]	51	30 children; 21 parents	4-8	Parents with recurrent or metastatic disease, receiving radiotherapy, chemotherapy or both	Parent's medical team	Evaluation of group by parent participants	Monthly meetings 1.5 hours; parallel children's & parents' groups.	None used	Themes of children's group included information and practical aspects of cancer, including visiting the hospital & information about treatment & equipment. Session on feelings & emotional expression. Parallel, facilitated, parent sessions included discussion about what to tell children about parental illness & developmental understanding	Parental feedback very positive. Parents indicated they would not attend a support group for themselves, but were highly motivated to engage in any support available for their child. Parents attended group due to concerns about their child's future & a desire for information & reassurance from professionals. Parents did not expect to benefit themselves, but found it a valuable experience	USA
Lewis, Brandt et al. 2015[37]	352	176 mothers; 176 children	8-12	Diagnosed within 6 months with Stage 0-III breast cancer	Parents' medical team in 6 US states; community cancer centres & self-referral	RCT	5 fully scripted patient education counselling sessions delivered at 2 week intervals to mother; interactive booklet about breast cancer read by mother to child; mother's workbook containing didactic text, in-session & at-home assignments completed by mother & child; child completed activity booklet about how child deals with stress. Access to patient educator via pager if required. Control group: mothers received printed booklet focussing on ways to support child about breast cancer; short (<10 mins) follow up call to review key points in booklet	Mother: CESDS; STAI; CSES; FPRS; PSC. Child: CBCL; RCMAS; CDI (maternal & child report)	Developing mother's listening skills; understanding child's experience as distinct from her own (strategies to prevent emotionally flooding child); attending to child's thoughts, feelings & concerns; strategies to support child who may be reluctant to share their feelings	Significant improvements in depression, parenting skills & child behavioural-emotional adjustment and depression relative to controls at 2 month follow up. At 1year post intervention, children of mothers in the experimental arm remained significantly less depressed compared to controls (child & parent report). Intervention did not affect parenting self-efficacy or maternal anxiety	USA
Murphy, Armistead et al. 2011[38]	160	80 mothers; 80 children	6-12 (8.7)	HIV	HIV/AIDS service organisations	RCT	Standard care plus 3 sessions; child development, pros & cons of disclosure, improving mother-child communication,	Mother: DSE; FRQ; PACS; PSI; RMHI; MOS SF-36; FC from FFS Child: CDI, PHCSCS; IPPA	Intervention targeted at enhancing familial communication & parenting skills specifically around	33% of intervention group & 7% of control group disclosed during course of study. Mothers in intervention group had increased disclosure self-	USA

							behavioural practice for disclosure. Control group: Standard care		disclosure, increasing readiness to disclose /disclosure	efficacy, increased parent-child communication & improved maternal emotional functioning. Children of mothers in the intervention group showed reductions in depression & anxiety & increases in happiness (regardless of disclosure status). Intervention helpful for mental health indicators, even if mothers did not disclose	
O'Malley, Beima-Sofie et al. 2015[69]	81	46 caregivers; 35 HCPs	7-15	HIV	HIV clinics	Evaluation of intervention	Book with cartoons to facilitate caregivers & HCPs gradual disclose. Includes information on medication and HIV	Semi structured interviews & questionnaires regarding HCPs' confidence in managing HIV disclosure & experience of implementing intervention	Disclosure of HIV book sharing	Caregivers & HCPs found book helpful in disclosing the child's HIV status & increasing their skills to facilitate their child's medication adherence. HCPs reported book reduced caregivers' reluctance to disclose	Namibia
Rochat, Mkwanazi et al. 2013[77]	48	24 mothers; 24 children	6-9 (7.8)	HIV	Re-enrolled from previous study conducted in the Africa Centre	Pilot study to establish feasibility and acceptability of the Amagugu intervention	6 session training intervention led by community worker for mothers & their children; written materials & games to prepare for & support maternal HIV disclosure to uninfected children; clinic and HCP training on child friendly clinical spaces	Qualitative measures of participants' perceptions of intervention, self-reported maternal health prior disclosure experience, disclosure level & impact on family. Disclosure classed as Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness	Amagugu Intervention: Communication using materials such as board games, playing cards, storybooks assisted parents in talking about HIV in a structured and clear way	All mothers chose to disclose something about their illness; half achieving full disclosure. Mothers' concerns about disclosure included child's emotional distress, risk of child disclosing to other people & managing child's questions about HIV. Children's reaction to disclosure (maternal report): 14 children calm & confident, 8 confused & 2 distressed or fearful. Materials were seen as culturally sensitive & helpful by community workers and stakeholders.	South Africa
Rochat, Arteche et al. 2014[52] and 2015[46]	562	281 mothers; 281 children	6-10	HIV	Re-enrolled from previous study conducted in the Africa Centre	Uncontrolled pre & post intervention evaluative of the Amagug	6 sessions at home; printed materials & child-friendly activities to prepare for & support maternal HIV disclosure to uninfected children	Mother: took child to clinic visit, completed child care plan, discussed care plan with child, legal guardian appointed and timing, GHQ, PSI, CBCL. Process evaluation data on maternal and	Amagugu intervention	60% of mothers 'fully disclosed' & 40% 'partially disclosed' their HIV status to their child. Mothers who perceived their health to be excellent were less likely to fully disclose compared to those considering their health to be poorer. More likely to fully disclose if in	South Africa

						u Intervention.		child experiences of intervention. Disclosure classed as Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness; No disclosure.		current partnership. Most children reacted calmly to full or partial diagnosis (maternal report). Children whose mothers fully disclosed were significantly more likely to react surprised & less likely to react confused. Mothers much more likely to report their child's reaction to the diagnosis as 'emotional'. Compared to partial disclosure, full disclosure associated with more children asking questions about maternal death. Maternal reported psychological distress & parenting stress decreased following intervention. Reduction in child emotional & behaviour difficulties (maternal report). Reductions in scores were not moderated by the level of disclosure (full/partial).	
Rochat, Mitchell et al. 2017[72]	562	281 mothers; 281 children	6-10	HIV	Secondary analysis of evaluation data in Rochat et al 2014 and 2015	Mixed methods	See Rochat et al 2014 and 2015	GHQ and parenting stress PSI; Child mental health CBCL Maternal reported data on: Most and least enjoyable parts of intervention; question children asked post disclosure; child emotional reactions to disclosure; child IQ (Ravens) Full disclosure using the words HIV; Partial disclosure using the words virus or illness.	Amagugu Intervention	61/281 children asked death related questions; most concerned about the threat of death, their mother's survival & prior family deaths. Children more likely to ask a death related question if their initial response had been fearful & their mother had regular income. Full disclosure led to increased odds of questions about death. Children who discussed the possibility of death with parents showed improved scores in post intervention evaluation (when controlling for baseline CBCL). Discussion of death did not increase psychological problems. Evidence that many children were aware of the effects of	South Africa

										HIV on family, hospitalisation, and deaths.	
Rochat, Stein et al. 2017[42]	928	464 mothers; 464 children	6-10	HIV	Primary healthcare facilities	RCT	Intervention group: 6 sessions at home; printed materials & child-friendly activities to prepare for & support maternal HIV disclosure to uninfected children. Control group: Enhanced standard of care of one clinic based counselling session.	Mother: PHQ-9, PSI, GAD-7, FAD, CBCL, took child to clinic visit, completed child care plan, discussed care plan with child, legal guardian appointed and timing. Disclosure classed as: Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness; No disclosure.	Amagugu Intervention	Higher rates of disclosure (partial or full) in intervention group (n=204 [87%]) compared to control (n=128 [56%]. Full disclosure was also more common in intervention group (n=150 [64%]) compared to control (n=98 [43%]) and time to disclosure was significantly shorter in the intervention group. Intervention participants were more likely to take their child to visit the clinic, develop care plan and appoint a legal guardian. No significant differences in mental health in either parents or children between groups. Significant improvements in the parent-child relationship in the intervention group.	South Africa
Rotheram-Borus, Lee et al. 2001[41]	719	307 parents; 412 adolescents	11-18 (14.8)	HIV	HIV /AIDS services database	RCT comparing group intervention with standard care	24 sessions focused on emotional reactions to illness, stigma, disclosure, conflict resolution & future planning. Attended by parents & adolescents (parallel groups)	Parent: BSI, Coping with Illness Questionnaire (5 subscales), custody plan parameters, count of multiple problem behaviours. Adolescent: BSI, count of multiple problem behaviours, conduct problems, RSES	Intervention group modules	Intervention group had significantly lower levels of emotional distress & family related stressors, fewer behavioural problems, higher self-esteem at 24 months follow up compared to control group. Parents reported lower levels of emotional distress & fewer problem behaviours. High levels of disclosure (both at baseline & 24 month follow up), similar for both groups.	USA
Thastum, Munch-Hansen et al. 2006[39]	75	24 mothers; 17 fathers; 34 children	8-15 (11.4)	Cancer	Somatically Ill Parents (COSIP) study	Evaluation of short term preventative counselling project	5-6 sessions (mean 4.75 sessions per family) focused on illness-related problems. Attended by family members, usually at home. Children also offered group counselling with other children participating in project.	Parent: BDI; FAD Child: BYI, IPPA, QMHRQoLCA. Evaluation of intervention by parents, children and therapists through semi structured interviews about experience of	Aims of intervention: facilitate open communication about illness, increase parental emotional availability, support parents in age-appropriate communication of	Significant decrease in depression for mothers & increase in family functioning (Communication & Affective Responsiveness subscales) for parents after the intervention. Significant decrease in depression scores for	Denmark

							Control group: TAU (families declined counselling)	intervention & adapted version of Therapy Evaluation Questionnaire	factual & emotional issues related to illness, enhance children's cognitive understanding of parental illness, recognise & accept needs & feelings, family coping & parental competence in parenting	children after the intervention. Parents' sought counselling to address concerns about how to support their children, difficulties in communication about problematic or emotional aspects of illness & conflict within family. Parents & children reported counselling helpful in terms of understanding emotional reactions of other family members. Counsellors' highlighted lack of open sharing of illness-related emotions within families, resulting in parental insecurity about how children felt, or whether children had someone who they could share their worries with. Content of counselling sessions address these concerns. Intervention rated positively by families	

BDI: Beck Depression Inventory
BYI: Beck Youth Inventory
CDI: Children's Depression Inventory
CES-DS: Center for Epidemiological Studies Depression Scale
CSES: Cancer Self-Efficacy Scale
DSE: Disclosure Self-efficacy
EORTCQoLQ: European Organisation for Research & Treatment of Cancer Quality of Life Questionnaire
FAD: McMaster Family Assessment Device
FC from FFS: Family Cohesion subscale from Family Functioning Scale
FPRS: Family-Peer Relationship Scale
FRQ: Family Routines Questionnaire
GCQ: General Communication Questionnaire
GHQ: General Health Questionnaire
IAS: Illness Attitudes Scale
IBQ: Interaction Behaviour Questionnaire

IDRCM: Illness & Death-related Communication Measure
IPPA: Inventory of Parent & Peer Attachment
IQoLCA: Inventory for Quality of Life in Children & Adolescents
MOS SF-36: Medical Outcome Study Short Form 36
PACS: Parent-Adolescent Communication Scale
PARQ: Parental Acceptance-Rejection Questionnaire
PHCSCS: Piers-Harris Children's Self Concept Scale
PSC: Parenting Skills Checklist
PSI: Parenting Stress Index
PPM: Perception of Parenting Measure
RCMAS: Revised Children's Manifest Anxiety Scale
RMHI: Rand Mental Health Inventory
RSES – Rosenberg Self Esteem Scale
SC-90: Symptoms Checklist-90 for adults
SC: Sense of Coherence
SDQ: Strengths & Difficulties Questionnaire
STAI: Spielberger State-Trait Anxiety Inventory
STAI-ch: State-Trait Anxiety Inventory for Children
QMHRQoLCA: Questionnaire for Measuring Health-related Quality of Life in Children & Adolescents
WHODAS-Child: World Health Organisation Disability Assessment Schedule for Children

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