Communication with Children and Adolescents about the Diagnosis of their own Life Threatening Condition

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Summary

When a child is diagnosed with a life threatening condition, one of the most challenging tasks facing healthcare professionals is to communicate this to the child, as well as to their parents or caregivers. Evidence-based guidelines are urgently needed for all healthcare settings, from tertiary referral centres in high income countries to resource limited environments in low and middle income countries, where rates of child mortality are high. We place this narrative review in the context of children's developing understanding of illness and death. We review the impact of communication on children's emotional, behavioural and social functioning, as well as treatment adherence, disease progression and wider family relationships. We consider the factors that influence the process of communication and the preferences of children, families and healthcare professionals about how to convey the diagnosis. Critically, the barriers and challenges to effective communication are explored. Finally, we outline principles for communicating with children, parents and caregivers, generated from a workshop of international experts.

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Introduction

One of the most daunting challenges for a healthcare professional (HCP) or parent is to tell a child that they have a life-threatening condition (LTC). This is not an uncommon scenario, with millions of children globally living with LTCs. An estimated 1.8 million children are infected with HIV,[1] and more than 300,000 children develop cancer each year.[2] In low and middle income countries (LMICs) where the burden of disease is greater, survival rates are often poor. While more than 80% of children with cancer in high income countries (HICs) now survive for more than five years, the overall survival rates in LMICs are as low as 10%.[2]

Talking to children about their diagnosis matters: it enables them to understand what is happening and improves their cooperation with procedures and adherence to treatment. In the longer term this will empower children and families to advocate for their care and treatment. This is especially important in LMICs, as highlighted by the recent Lancet Commission which found that access to healthcare in this context is often unconscionably low.[3]

The moment that the diagnosis is conveyed is often remembered vividly for many years and signals the beginning of a new trajectory for the family. Within some contexts, mainly in LMICs, HCPs are often faced with LTCs and death, while for others it may be a relatively rare occurrence. Sensitive and developmentally appropriate communication matters enormously to children and their families regardless of their life circumstances. Available recommendations from HICs have considered how to break bad news to parents and adult patients,[4,5] but do not specifically address the delicate task of communicating directly with children about their diagnosis. Without such guidelines this difficult and emotionally challenging responsibility[6] is sometimes avoided, in part through fear of how the child and their family may react.

Healthcare philosophy about sharing information with children regarding their illness and prognosis has changed significantly over the last 70 years.[7] Until the 1960s prevailing practice was to withhold the diagnosis, or its life threatening nature, in the hope that this would protect children from distress. Over subsequent decades the importance of disclosure was increasingly recognised, in part reflecting advances in medical treatment (and thus children's survival) and greater appreciation of children's developmental level of understanding about illness and death. More recently the debate has evolved to a more nuanced and personalised consideration of what, when and how much a child should be told about their diagnosis. Furthermore, acknowledgement that the whole family is affected when a child is unwell has resulted in adoption of family-centred models of paediatric care, which consider the impact of the illness on siblings, parents/caregivers.[8] The traditional relationship between doctors and patients has also changed, resulting in a shift in the doctor's role to promote patient empowerment and shared decision making.[9] In resource constrained settings where access to qualified HCPs may be limited, the transferability of these models remains a challenge, particularly in over-burdened health systems.

In seeking to improve communication, HCPs and parents/caregivers alike must be aware of the cognitive, emotional and psychological development of children and adolescents in relation to their understanding of death, as well as the cultural and religious beliefs held by the child and family around disease, dying and death. Consideration of these factors will ensure that communication is appropriately tailored to avoid misunderstanding.

Cognitive and emotional developmental stages and conceptualisation of LTC

Consistent with broader Piagetian-based models of cognitive development, children's understanding of illness and death evolves over time, starting with more concrete, clearly defined subcomponents with gradual acquisition of more complex and abstract components (Box 1).[10]

BOX 1: Chronology of acquisition of concepts of death beginning at approximately age 5 years, with full understanding around 10 years.

Concept	Description
Irreversibility	Once the physical body is dead, it cannot be made alive again.
Personal mortality	Death applies to oneself.
Universality	All living things must eventually die.
Non functionality	Once a living thing dies, all life-defining capabilities (such as walking, seeing, thinking) end. Non corporeal continuation can be considered a separate concept i.e. that there may be some form of personal continuation after death, such as the soul or spirit, which may be capable of life-like functions after death such as loving or helping.
Causality	Realistic understanding of events that might cause death.

Children under the age of 2 have an awareness of object permanence and are developing a mental image of a parent/caregiver, becoming distressed when they leave and seek their return. Children aged 3 and 4 understand death as a departure, and part of the natural order of life, but when someone has died it is important for parents/caregivers to repeat the key message that the dead person will not, and cannot return.[11] It is not typically until the age of 5 or 6 years that children understand the finality and irreversibility of death,[10] although recent work suggests that some children may acquire this as early as 4 years old.[12] Other important components include the understanding of personal mortality (that death applies to oneself) around the age of 5 and unpredictability (the time of death is not knowable in advance). By the age of about 9 years, children have a more complete understanding of death.

Children's understanding of what *causes* illness and death is significantly influenced by what is known as "magical thinking", between the ages of 4 and 7 years.[13] "Magical thinking" is used to describe children's belief that thoughts, events or wishes can cause external events e.g. that illness can be caused by a particular thought or behaviour. Concurrently children have an emerging sense of conscience, but poor understanding of how illness is spread; this can easily lead to misattribution of cause and consequent guilt (e.g. illness is a punishment for their poor behaviour).[11] This highlights the importance of ensuring that the language used with children is concrete and specific to avoid misunderstanding or incorrect inferences about the cause of illness or death.[11]

A major shift in children's understanding of key biological concepts about the structure and function of the human body and disease transmission takes place between the ages of 7 and 11 years.[13] At this stage children also use their emerging reasoning skills more successfully with concrete information rather than abstract concepts, or things that are invisible inside the body. For example, they can understand changes related to cancer such as hair or weight loss because these are tangible and observable. However, a fuller understanding of "cancer", chemotherapy or side effects may be more difficult to understand.[14]

Recent advances in understanding brain maturation during adolescence are reflected in a shift towards extending the adolescent age range to 24 years.[15] Higher order cognitive processes including executive functions (e.g. inhibitory control, planning and decision making) undergo gradual development during adolescence.[16] Adolescents' focus on short term consequences is particularly relevant for their decision-making about treatment and may contribute to tension between the different priorities of patients and HCPs e.g. an adolescent's desire for independence and the HCP's focus on a timely treatment regimen.[17] There is a substantial increase in the salience and influence of peers; establishing and maintaining peer group identification is complicated by social isolation due to periods of inpatient treatment, or feeling or looking different due to their LTC. Adolescence also involves establishing autonomy from parents/caregivers, which may conflict with periods of increased dependency during treatment. The incidence of depression and anxiety peaks during adolescence, making this a time of increased vulnerability.[18] Recognition of the specific developmental challenges of LTCs during adolescence is reflected in service innovations for adolescents and young adults with cancer in HICs.[19]

Developmental models rarely consider the potential influence of children's prior experiences and exposure to illness and death on their understanding of these concepts. A number of case reports[20] and anthropological studies[21] suggest young children (age 5-7 years) can be aware of their impending death. Empirical studies indicate that children who have had greater experience of death (through living in areas where illness or armed conflict are endemic) have a relatively advanced understanding of death,[22,23] although the evidence is limited and inconsistent.[24,25]

In the emotional turmoil of distressing news, children may function as if they had a less developed understanding of death than their chronological age might suggest.[11] The specific needs of children with cognitive or sensory disabilities must also be considered. Whilst these children are more likely to suffer significant ill health, their communication needs are often poorly met in healthcare settings[26] which may adversely affect their outcomes.[27] National Institute for Health and Care Excellence (NICE) guidance recommends that for all children with life limiting illness, information delivery should take into account both their age and level of understanding.[28]

Cultural understanding of death

Culture and traditions, ethnicity, religious and spiritual beliefs will also influence children's and parents'/caregivers' perspectives on the meaning of death and illness e.g. possible reluctance in Catholic communities to disclose LTC because it could preclude hope and faith.[29] Conceptual understandings of death vary widely across the globe e.g. a study in South Africa described how death can be seen as a transformational experience in which communication remains possible with deceased family members.[30] The way these factors interact requires HCPs to explore an individual's belief system to ensure the information communicated is meaningful, and enable the HCP to avoid stereotypes and recognise the different cultural and religious reference points of family members.[31]

Aim of the review

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

1a) What is the impact of communication about a LTC on children and adolescents' emotional, behavioural and social outcomes; illness related factors including adherence to treatment, disease transmission and progression? 1b) What is the impact of the communication on their parents/caregivers and the wider family system?

2) What factors influence the process of communication and what are the barriers and challenges to communication?

3) What are the reported preferences of children, adolescents and parents/caregivers about the way diagnostic information is conveyed?

The outcomes of the narrative review and previously published recommendations[5,32] formed the basis of discussion at a workshop of international experts in 2017 to generate a framework of communication principles.

Methods (see appendix)

Results

Findings of the Review

The results of the narrative review are presented in relation to our three research questions; details of each study in the review are summarised in Table 1 (appendix). The varied literature has disproportionately focused on the experience of families and children with cancer in HICs, and HIV in LMICs.

Although rarely a primary question of research studies, there is wide variation in whether children are told about their diagnosis, and how to do it. Research from Italy exploring parental communication with their children (n=64; 4-18yrs) who had cancer suggests that nearly 20% of parents (n=64) did not talk to their children about the disease[33], and 64% of parents (n=86) in the Netherlands did not discuss impending death with their child (1-17yrs).[34] Non-disclosure rates to children infected with HIV are high, with a recent systematic review of 22 articles representing 12 LMICs indicating the proportion of children who received full disclosure ranged from 1.7% to 41%.[35] A review of 31 studies describing patterns of HIV disclosure found that the proportion of children who knew their status was lower in LMICs (median 20.4%) than 'industrialised countries' (mostly USA) (43%).[36] There may also be discrepancies between caregivers' beliefs about the importance of disclosing a diagnosis of HIV and their own disclosure practice. A survey of caregivers (n=271) of HIV infected children (6-16yrs) in Kenya found that 79% of carers believed children should know their HIV status, although only 19% had disclosed to their children.[37] This highlights the importance of identifying the barriers which impede communication.

Following the early work of Bluebond-Langner[38], studies exploring children's views consistently report the importance of honest discussions about illness, prognosis and death. A survey of adolescents (n=17; 14-21yrs) with cancer in the USA found 75% indicated a preference for end-of-life discussions not only “if dying” but at an early stage of the disease.[39] A qualitative study in the Democratic Republic of Congo (DRC) (n=19; 10-21yrs) explored the experiences and reactions of children to disclosure of their HIV status; although some reacted with surprise, sadness and worry, many felt relieved to have an explanation for their illness and most reported that it was better to know their diagnosis.[40]

1a) What is the impact of communication about a LTC on children and adolescents’ emotional, behavioural and social outcomes; illness related factors including adherence to treatment, disease transmission and progression

Emotional, behavioural and social outcomes

Studies have identified benefits of communication for children and adolescents across a range of outcomes, although this is not universal. In the oncology literature a Dutch study of children with cancer (n=56; 8-16yrs) who received earlier information about their diagnosis and prognosis reported fewer symptoms of anxiety and depression compared to children who received less information or information at a later stage.[41] An Italian mixed methods study of communication between children treated for a brain tumour and their parents systematically classified parents’ communication against a number of key objectives (such as the completeness and consistency of information given).[33] Psychological indicators of distress, including withdrawal, anxiety/depression and social problems, were significantly more infrequent when communication was classified as effective, as compared to avoidant or ineffective.[33] Retrospective reports from parents (n=86) whose children (n=56; 1-17yrs) had died from cancer 3-8 years previously identified reducing their child’s fear as one of the benefits of talking to their child about death.[34]

Several studies have explored the impact of the disclosure of an HIV diagnosis on children’s psychological wellbeing. A quantitative study in the USA of children (n=196; 8-16yrs) with perinatally acquired HIV and their carers (n=196) found lower levels of anxiety in children who knew their HIV-positive status.[42] HIV-positive adolescents (n=127; 11-15yrs) in Zambia whose HIV status had not been disclosed reported significantly higher levels of emotional difficulties than those who knew their diagnosis.[43] Delayed disclosure may have a negative impact, with children reporting feelings of anger and betrayal that they had not been told earlier.[44,45] HCPs in a South African study reported early disclosure reduced children’s sense of being deceived.[46] Other studies have shown neither significant benefits, nor adverse effects of disclosure, for child or family-relationship outcomes.[47]

Children (n=77; 3-13yrs) may experience a range of emotions at the time of disclosure about their diagnosis including shock, sadness, anger, worry and confusion, although these negative emotions do not always persist.[47] A group of children in Puerto Rico (n=40; mean age 13.8yrs), reported very low rates (5% or less) of sadness, depression and worry 6 months after disclosure of their HIV status and 70% described feelings of “normalcy”.[48]

A prospective, observational study of the psychosocial impact of a paediatric HIV disclosure programme in Thailand (n=160; 7-18yrs) showed improved social functioning at 6 months follow-up, in addition to a small but significant decrease in depressive symptoms.[49] Improved communication may alleviate uncertainty and consequently improve quality of life. Greater uncertainty about the illness and treatment in children (n=120; 8-18yrs) receiving cancer treatment was associated with poorer overall health-related and cancer-related quality of life (after controlling for age, anxiety and pain).[50]

Treatment adherence, disease transmission and progression

Children with LTCs can have painful investigations and lengthy treatment regimens with unpleasant side effects. Communication between the child, their parents/caregivers and HCPs helps to gain the trust of the child and is associated with enhanced adherence through improved understanding of illness and the importance of treatment.[51,52] A study in South Africa of adolescents (n=684; 10-19yrs) with HIV found that knowledge of HIV status doubled the odds of self-reported full adherence to their drug regimen.[46] Similarly, a prospective cohort study in Zambia (n=96; median 6yrs) found that compared to those who knew their HIV status, children who did not know had poorer antiretroviral therapy (ART) adherence.[53] Improved medication adherence is consistently cited as a benefit of HIV status disclosure from several qualitative studies from the DRC, Uganda and Nigeria.[54-56] Children have even reported refusing medication as a strategy to obtain additional information if caregivers were reluctant to explain the purpose of the treatment.[45]

Children's understanding and awareness of an HIV diagnosis potentially reduces risky behaviours which can lead to the transmission of HIV. Research in Brazil (n=36; 1-15yrs) found that HIV-positive adolescents had little communication about their diagnosis, resulting in a poor understanding of the risks of unprotected sex or donating blood.[57] A qualitative study in the DRC (n=8; 8-17yrs) reported that children viewed the ability to protect others from infection as an important advantage of knowing their diagnosis.[58] In a study in the USA (n=196 caregivers and children) children and adolescents (8-16yrs) who had been aware of their HIV status for longer reported greater *intention* to disclose their status to sexual partners.[42] Disclosure may *actually* prevent risky sexual behaviour as HIV-positive adolescents who were aware of their status were more likely to consistently use condoms than unaffected peers.[59]

A child's knowledge of their HIV status may have implications for the progression of their disease. A retrospective database analysis in Romania (n=325; 5-17yrs) found that children who did not know their HIV diagnosis were more likely to have compromised immune function as measured by reduced CD4 counts, or even die.[60] Evidence from the USA suggests that children (n=64; 8-18yrs) who had recently disclosed their HIV status to friends had improved CD4 counts over subsequent months (but no changes in either self-concept or behavioural problems).[61]

1b) What is the impact of the communication on their parents/caregivers and the wider family system?

Evaluation of a disclosure model for paediatric patients with HIV (n=40; mean age 13.8yrs) in Puerto Rico found the disclosure process helped a significant proportion of children and adolescents feel more supported by parents (57%), grandparents (48%) and clinic staff (48%).[48] Indeed, 85% of the participants considered disclosure as a positive event for them and their families. Caregivers' comments reflected a sense of relief at no longer lying or continuing to hide a secret from their children.[48]

The relationship between communication and outcomes for parents/caregivers has also been explored. A retrospective Swedish survey of bereaved parents (n=449) whose children had died from cancer at least 4 years previously found that of the 147 parents who had talked to their child about death (a third of all participants), none regretted it.[62] Of the parents who had *not* talked to their children 27% said they regretted their decision, and there were higher levels of current parental anxiety and depression within this sub-group.[62]

A study of the communication between HCPs and parents of children with cancer (n=304) in Egypt demonstrated significant relationships between parents' satisfaction with the doctor's communication style and trust in their child's physician.[63] Furthermore, trust was key to improvements in patient adherence and a more positive view of the future.[63] A US retrospective study of parents (n=103) whose children had died from cancer (mean age 10 years at death), found that a shared acknowledgement between HCPs and parents of the seriousness of the prognosis was associated with better quality of care at home (parent-rated) and earlier consideration of hospice provision.[64]

2. What factors influence the process of communication and what are the barriers and challenges to communication?

The process of communication with a child around major illness is dynamic, influenced by a number of factors within the triad of patient (child/adolescent), parent/caregiver and HCP relationships which may either facilitate communication or create barriers (figure 1). These factors can evolve over time with changes in knowledge of the condition, disease progression and developmental understanding.

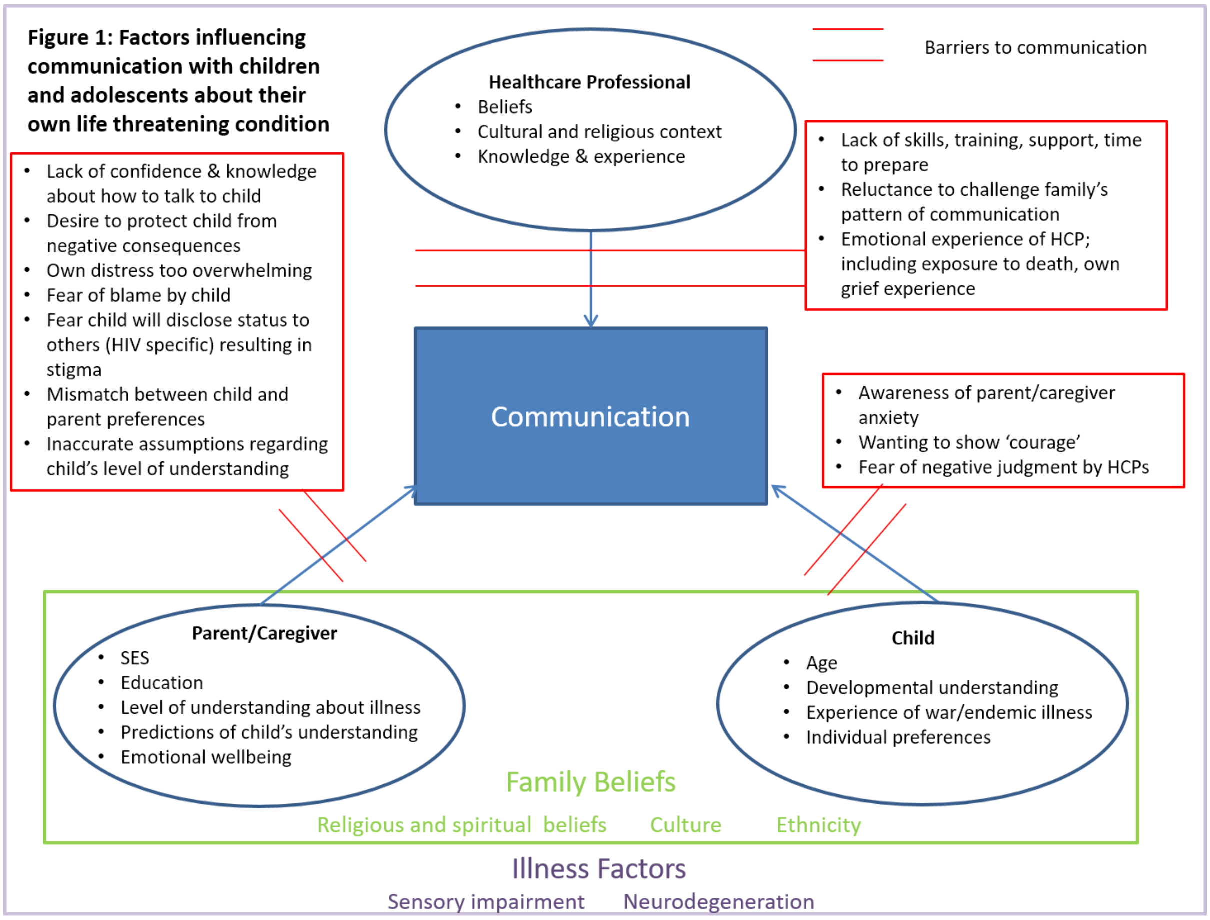
Figure 1: Factors influencing communication with children and adolescents about their own life threatening condition

Child Factors

While many children and adolescents want information about their illness, including discussions as to whether they may die, this is not universal, with estimates of one third to one quarter of adolescents not wanting this information.[39,41,65] In a US mixed methods study of survivors (n=52; 7-21yrs) of childhood cancer, some "well-adjusted" survivors had "embraced their cancer" and become experts and advocates, whereas others had "encapsulated the illness" and "acknowledged it as little as possible".[66] Some survivors of childhood cancer reported that their own lack of understanding and awareness of their illness at the time had helped them to cope.[66]

A retrospective study of bereaved parents (n=86) found that of those (n=55) that did *not* talk to their children (1-17yrs; median age 7 years) about death, some had based their decision on the perception that their child did not wish to discuss their own death.[34] Children (n=38; 4-19yrs) may be unwilling to talk, or feel inhibited about raising their concerns[67], particularly if they are aware of their parents' anxiety and discomfort around the subject.[68] Wanting to show courage and fear of negative judgement from HCPs can also inhibit children's communication.[67]

Child Demographic Factors

Parents and caregivers in a number of studies from HICs and LMICs highlighted a concern that their child was too young to understand their diagnosis,[34,56,69-71] and that more information is shared with older children,[33,59,62,72,73] with systematics reviews of paediatric HIV disclosure concluding that children between the ages of 10 and 15 years are usually told their HIV status.[59] A quantitative study from the DRC (n=201; 5-17yrs) reported sexual debut as a trigger for caregivers to disclose adolescents' HIV status to them.[74] However, it is important to differentiate between the quantity of information shared and the effectiveness of communication. Analysis of the communication between parents and children (n= 64; 4-18yrs) surviving a brain tumour found communication varied with the child's age.[33] 'Avoidance of communication' was most frequent with the youngest children, whereas ineffective communication was more frequent with the older age groups. Parents may underestimate younger children's understanding, which leads to information being omitted. Conversely, parents may over-estimate older children's understanding and provide too much detail or at too complex a level.[33]

School attendance, child's educational level, children on ART, urban versus rural residence, having a caregiver who has self-disclosed their own HIV positive status, religious and spiritual beliefs have all been explored in relation to HIV disclosure.[59] A study of perinatally affected children (n=77; 3-13yrs) living in the USA found no association between child knowledge of HIV and gender, ethnicity, caregiver education, parent/caregiver-child relationship factors, adoptive versus biological placement or other health status indicators; this study was conducted in the pre-ART era.[47]

Parental/caregiver factors

Parents/caregivers are often the interface between HCPs and the child or adolescent. Parents may adopt (or be delegated) a range of different roles[71,72] in the communication triad[75,76] which are dependent on a number of factors (Box 2).

BOX 2: Roles parents and caregivers may take in the triadic exchange of information

- Facilitators of communication[76]
- Envoy (acting as a go –between for patient and HCP)[76]
- Human "database" (holding information to answer questions)[76]
- Human buffers (using parents to answer difficult questions)[76]
- Communication brokers (to repeat or clarify information)[76]
- Filtering and limiting upsetting information[77]
- Confidantes (listening to children's private opinions)[67]
- Allies (using language to support expression of preferences)[67]
- Emotional safety and support[67]

Understanding, beliefs and the response to information about a child's LTC

Parental communication is linked to parents' own understanding and emotional response to the diagnosis. A study of UK-based parents (n=55) of children (3-18yrs) diagnosed with leukaemia explored the impact of parental perception of illness on the information they subsequently communicated to their children.[72] Parents who believed the diagnosis was incurable and would result in death were less likely to inform their child that the diagnosis was cancer and gave as little information as possible. In contrast, parents who described themselves as too shocked and unable to grasp the information were more likely to tell their child as much as they understood, including the cancer diagnosis.[72] Thus high levels of parental shock can lead to potential miscommunication or misinterpretation of information, which in turn is passed on to their child. Parents' decisions not to talk to their child may also reflect their own emotional distress and a desire to protect themselves from the "unbearable" reality of the situation.[68]

Parents may struggle to anticipate or react to worries their child may have. Parents frequently reported lacking confidence in their ability to answer difficult questions, particularly those about death. [34,56,69-71] A qualitative study in the DRC found that caregivers (n=8) were sometimes unaware that their children (n=8; 8-17yrs) had outstanding questions or concerns after HIV disclosure.[58]

There is variation in parental beliefs about talking to children about LTCs. A study of bereaved parents found that while those who talked to their child about death did not regret it, over 70% of those who had chosen *not* to tell their child did not regret their decision.[62] A Dutch study of parents (n=86) whose child had died 3-8 years previously, reported that 36% did discuss their child's impending death with them, of whom 80% reflected positively. Of those who did *not* talk about death with their child, 60% reflected positively. The authors conclude that parents need support making this decision.[34]

Parental/caregiver education and sociodemographic background

Parental/caregiver educational level can influence communication, although the literature is inconsistent. A cross sectional study of caregiver-child dyads in Ethiopia (n=390; 1-14yrs) found higher rates of disclosure among caregivers who were illiterate compared to caregivers with a higher educational level.[78] A similar finding was noted in a Thai study of caregivers (n=103) of HIV infected children (6-16yrs).[79] Conversely a study in the USA found that children who knew their HIV status were more likely to come from families with a higher socioeconomic status.[80]

Desire to protect child from distress

Parents/caregivers may not appreciate the potential importance of communication[68] and frequently express a desire to "protect their child" fearing that disclosure will have negative psychological consequences for their child including distress, depression, anxiety, isolation and loss of hope.[34,56,70,71,79] Other parents reported that they did not want to challenge their own, or their child's hopes that the illness might be cured.[34] For some parents, death was not seen as an appropriate topic to talk about with children.[34]

Parents/caregivers of children with HIV sometimes feared that disclosure would prompt children to ask difficult questions about the source of HIV, and blame, resent or lose respect for their parent.[56,70] The stigma associated with an HIV-positive status can create concern for parents/caregivers that the child will disclose their status to others, with negative consequences not only for the child, but the whole family.[36,56,70] Similar sentiments were not reported in the literature pertaining to cancer.

Parental emotional wellbeing

Parental mental health may also influence communication. A cross sectional study of children with cancer and their mothers in the USA (n= 94; 5-18yrs) found mothers' symptoms of depression were associated with their observed communication style (e.g. maintaining the same topic as the child, maternal reflections on children's contributions to the illness-related discussion).[81] Mothers with more symptoms of depression were rated by observers as having a more negative communication style and were less warm, supportive and responsive when interacting with their child.[81]

Factors influencing HCPs' communication

The HCPs' contribution to the triad of communication (child, parent/caregiver and HCP) is also influenced by their own beliefs, cultural and religious context, experience and knowledge, both at a professional and also personal level (figure 1). Barriers reported by HCPs include a lack of skills, training and time to prepare for discussions and reluctance to challenge a family's "avoidant pattern of communication".[68,82] The paediatric oncology literature identified barriers including "a lack of provider knowledge, experience or comfort; clinical uncertainty; a lack of patient/parent comfort or readiness; unrealistic parental expectations; and a lack of cultural support".[83] There are specific stressors associated with working with patients who are seriously ill which may impact on HCP's ability to communicate effectively with their patients and include: frequent exposure to death; a lack of time to spend with dying patients; a growing workload and large numbers of deaths; coping with one's own emotional response to dying patients; the need to carry on "as usual" in the wake of patient deaths; communication difficulties with dying patients and relatives; identification with, or developing friendships with patients; an inability to live up to one's own standards (e.g. internalised responsibility to provide a "good death") and feelings of depression, grief and guilt in response to loss.[84] Frequent exposure to death may activate HCP's own memories of unresolved loss.[85] HCPs can feel helpless that they were not able to prevent a child's death or spare the family emotional anguish.[85] The emotional impact of these issues can lead HCPs to feel ill-equipped to support children and their parents/caregivers, and could contribute to the high levels of psychological morbidity reported in UK clinicians (40% in 2002) and medical students.[86] HCP's strategies to manage their painful feelings in response to these challenging situations may include creating a physical or emotional distance between themselves and the family through busyness, impatience or formality, which can further impede communication.[87,88]

Conversely, there is some evidence that HCPs involved in palliative care have comparable levels of stress and "burnout" relative to colleagues in other specialities.[84] This may reflect service related factors within palliative care, such as high quality staff support which mitigate some of the stressors associated with working with dying patients.[84,89] This indicates support structures are key for HCPs dealing with LTCs in different healthcare contexts, but may only be aspirational in resource-constrained settings.

Differences in views, needs and preferences within the triad

HCPs and parents (n=38) may have very different views about how much information should be shared with the child, often originating from parents' desire to "protect" their child (n=16; 13-19yrs at time of diagnosis).[17] Although HCPs may advocate an "open and honest" approach to disclosure and information sharing, parents may disagree[77]particularly around perinatally acquired HIV.[90,91] Accurate information supports congruence between a child's internal world (i.e. awareness of their illness, changes in their body, people's reactions and possibly their imminent death) and their outer world (i.e. information from parents and HCPs).[62] There can be a mismatch between parents' and children's preferences for communication.[75] If the child is absent or excluded their knowledge and understanding of the illness is likely to be determined by the parent. Studies highlight that children may learn about their disease and how serious it is without being explicitly told.[21,92] The parent and child may each attempt to protect the other from their own awareness of the disease by not acknowledging it. This 'mutual pretence'[7] may have negative consequences if the child feels alone in making sense of frightening knowledge without any support to manage the emotional consequences.[87] Some families' usual style and coping mechanism is not to communicate; while this needs to be respected it should not be assumed that the child does not want information, and the possibility of discussing the child's diagnosis should be re-visited. Increasing autonomy during adolescence can also result in parents/caregivers and adolescents holding contrasting views about treatment decisions. These situations are both ethically and emotionally challenging for HCPs, especially if the HCP has a strong opinion themselves.[17]

3. What are the preferences of children, adolescents and parents/caregivers about the way diagnosis and information is conveyed?

Studies have investigated the preferences of parents/caregivers and children regarding *what* and *how* diagnostic information is communicated (Box 3). The majority of participants were adolescents with cancer, predominantly from HICs, but their views offer invaluable practical guidance for HCPs which may be applicable across multiple healthcare settings.

BOX 3: The preferences of children, adolescents and parents/caregivers about the way diagnosis and information is conveyed

Preferences about how information is communicated

1. **Relationship with HCP**: Trust, honesty and empathy of HCPs highlighted by qualitative studies of children, adolescents and parents (child and adolescent patients[17,93,94], parents[93,95])
    a. Adolescents valued a professional-friendly relationship in which they felt the HCP was genuinely concerned and interested in them as an individual, rather than a collection of symptoms[93]
    b. Respect within the relationship (adolescent report)
        i. Demonstrated through the way staff recognise and negotiate an adolescent's priorities and competing demands (e.g. maintaining social relationships around treatment)[17]
        ii. Communicated through sensitivity to cues that adolescents may not want to talk at a particular moment[67]
        iii. Large ward rounds feel an invasion of privacy for adolescents; preference for separate discussions[94]
    c. Respect within the relationship (parental report)
        i. Facilitated by the doctor looking at them, greeting and addressing them by name[95]
        ii. Demonstrated through recognising their parental role and being acknowledged as the experts about their child[93]
        iii. Honesty extends to explicitly acknowledging the limits of professionals' knowledge[93]
        iv. Importance of empathy, particularly in situations of poor prognosis, when parents have limited experience of serious illness, or conversely, when parents work in healthcare and consequently hold substantial knowledge[73]
2. **Language:**
    a. Direct, clear and as simple as possible[73,94]
    b. Tailored to their particular age group (rather than "one size fits all")[93]
    c. Balance between being understandable but not overly simple or "baby-ish"[67,93]
    d. Avoid technical jargon; experienced by adolescents as an attempt to keep them powerless[94]
    e. Straightforward approach particularly around sensitive topics such as side effects, prognosis and fertility (sperm banking[94]/oocyte preservation)
3. **Adequate time for consultation:**
    a. Enables information to be paced, questions answered and clarification sought on both sides[17,73,94]
    b. Parents, children and adolescents recognise the impact of the initial shock of diagnosis; want time in order to come to terms with upsetting information[93]
    c. Opportunity to ask questions; staff need to recognise that this is not always straightforward for children and adolescents, so they may need help to do so[67]
    d. Information about the timing of meetings to discuss their care; this was prompted by a desire not to get up too early (adolescents) or to ensure adequate preparation and attendance (parents)[93]
    e. Some adolescents wanted discussions with HCPs without their parents present [94] [96]
4. **Continuity of care**:
    a. Preference for consultations being with same HCP (where possible) throughout treatment (adolescents and parents)[93]
    b. Consistency in the language and terms used[93]

    c. Avoid potential miscommunication between HCPs or the need to repeat explanations or medical history to different HCPs[93]

5. **Sources of information:**
    a. Increasing dominance of adolescents' wider social network reflected in adolescents' reports of their preferred sources of information about their illness e.g. adolescents with cancer preferred to discuss cancer with their HCP first, followed by another teenager with cancer, and finally their parents[94]; questionnaire surveys of adolescents with cancer indicating a preference for greater direct involvement with HCPs in adolescence[96]
6. **Location of conversations:**
    a. Parents strong dislike of having prognostic discussions in earshot of their unconscious child as they felt concerned that "negative talk" may adversely affect their child[97]

Preferences about what information is communicated

1. **Information about illness and treatment:**
    a. Parents acknowledge impact of shock on their ability to understand and retain information[95]
    b. Importance of checking understanding, repeating information, offering early follow-up and written information[93,95]
    c. Information about immediate and long term future[94]
    d. Adolescents wanted more information including treatment and possible side effects, common emotional reactions, treatment timescale, likelihood of recurrence and long term effects such as their ability to have children[67,94]
2. **Prognosis:**
    a. Parents want as much information as possible; understanding of prognosis explained carefully in terms of likely time scale of events and providing detail of survival statistics.[98] Where this is not possible or available, parents wish to have the limits of available information and uncertainty acknowledged[97]
        i. Prognostic information very helpful in maintaining hope regardless of their child's prognosis[98]
        ii. Parents who described being very upset by the prognosis still wanted this information, and wanted additional information more frequently than parents who were not upset.[98] This is important as HCPs may consciously or unconsciously tailor information on the basis of the reaction of the parent[98]
3. **Decision-making:**
    a. Families felt their decision making was supported by honesty, trust, being given time to decide, discussions of risks and benefits and understanding choices[83]

Preferences about who should be involved in communication

1. **Age:**
    a. Consensus towards greater inclusion of children in consultations with increasing age[6]
2. **Presence of child:**
    a. Parental reservations about child being present include feeling unable to ask specific questions around prognosis; being concerned about the potential emotional impact of their own distress on their child.[75] Conversely parents report less distress when their child was present at the initial conversation about diagnosis and treatment.[75]
    b. Parents, particularly mothers, of younger children sometimes feel distracted by their child's "demands" while trying to attend to the medical consultation[75]
    c. Cultural and contextual differences in expectations of who should talk to the child about their illness. In some settings HCPs and caregivers view caregivers as the most appropriate person to lead HIV disclosure conversations.[99,100] Conversely in Ethiopia caregivers believed the doctor should be responsible for disclosing HIV status to the child.[78] Caregivers of children with HIV in the USA valued discussions with HCPs to

prepare for conversations with their child about the diagnosis and often cited the HCP as the most appropriate person to talk to their child.[101] A South African study found parental/caregiver discussion about disclosure with a HCP was associated with disclosure to the child; 96% of parents/caregivers who had not discussed disclosure with a HCP reported that they would like to talk to a HCP about disclosure.[102]

Ethical perspectives

Ethical and moral arguments are pertinent to communication with children with LTCs. In the UK, the NICE guidelines recommend that children can be active stakeholders in all aspects of advance care planning.[28] Paediatric cancer patients are frequently enrolled into clinical trials and an ethical case is often made for communication as it facilitates the process of obtaining assent/consent for participation in trials and promotes the emerging autonomy of the child.[103] It is important to respect young people's wishes regarding what information they do and do not want[77] and to take account of their developmental capacities whilst upholding the principles of the UN Convention on the Rights of the Child.[104]

Expert Group Workshop and Development of Framework

The expert group of clinicians and researchers with extensive experience of working with children and families affected by LTCs in HICs and LMICs met for a two day workshop in Oxford, UK in 2017. The group used the outcome of the literature review, previously published recommendations[5,32] and integrated these with their academic and clinical perspectives. This iterative process resulted in a framework of principles to facilitate HCPs in communicating with families (Box 4). These are guiding principles; it is not expected that every principle applies to every situation and each HCP should also use their clinical skill and judgement for each family, recognising cultural differences that influence what is considered appropriate to discuss with children. It is important to be aware of the circumstances e.g. in an acute situation the child and parent/caregiver may be unable to assimilate large quantities of information (due to physical symptoms such as fatigue or pain, as well as emotional distress). Key messages must be prioritised, repeated and understanding checked.

Limitations and Future Directions for Research

Despite the potential benefits of effective communication, many children are not told about their diagnosis. The global prevalence of LTCs in children makes it an urgent priority to develop robust, child-focused communication guidelines and a research agenda to address the limitations and gaps in the literature.

Limitations of the research literature include the wide age range of participants and stage of the illness. Some work has explored these issues by actively recruiting participants at specific points on their treatment journey.[41] The reviewed qualitative studies are dominated by interview accounts; analyses of recorded consultations are rare, but could advance our understanding. A proportion of studies do not have relevant control/comparison groups which makes evaluating the impact of communication difficult to determine. There is almost a complete lack of adequately powered, controlled evaluation studies, especially randomised controlled trials (including pragmatic trials), to evaluate interventions or best practice.

Openness is a consistently recurring theme within the literature, but is usually poorly defined or quantified with an implicit assumption that it relates to an explicit and honest exchange of information between the child and parent/caregiver or HCP. Moreover, the informational or emotional content and developmental appropriateness of the communication is rarely specified or evaluated. This should be addressed in future research.

It may be perceived as difficult to initiate research at such a vulnerable time in a family's life, with ethics committees and staff (understandably) protective of this patient group. However, research with recently bereaved parents (n=69) indicated that while many were initially motivated by altruistic reasons to take part in research, participants subsequently reflected that they had found it personally helpful.[105] We should therefore consider how to sensitively involve children and parents/caregivers in research closer to the moment of diagnosis.

Most research is restricted to cancer (in HICs) and HIV (predominantly in LMICs) which does not reflect the global prevalence of LTCs, or children with acute LTCs. Globally, most children live in LMICs and more research must be devoted to their healthcare needs, as well as the ever expanding situations of violence, war, poverty and the effects of climate change. Addressing the needs of younger children and those with disabilities in both HICs and LMICs needs to be an important priority.[28] This review is limited to consideration of the ill child, but their condition is likely to impact on children in the extended family, particularly siblings who may have differing developmental needs. The framework of principles (box 4) is could be useful for siblings, but further work is required. Parents'/caregivers' and children's increasing ability to access information independently through the internet creates both opportunities and challenges which impact on the communication relationship with HCPs. Communication skills are a key component of training curricula for HCPs, but the impact of such training on clinical practice has rarely been evaluated,[4] or the barriers which impede implementation.[4] More extensive communication skills training and ongoing support programme are required in both LMICs and HICs.

Communicating the diagnosis of LTC to a child is not a single event and evolves over time and illness trajectory, including supportive discussions about management and prognosis. However, the moment of diagnosis serves as the foundation for a longer term communicative relationship between the HCP, parents/caregivers and child.[106] Effective communication requires an understanding of how the parent/caregiver and child perceive the situation, the transfer of factual information and also emotional scaffolding for parents, caregivers and families. Providing emotional support to families is time consuming and undoubtedly has an impact on HCPs; support to process the personal impact of this work is crucial to ensure HCPs are able to cope with the emotional demands of this work.

BOX 4: Principles to assist health-care professionals in communicating with children, adolescents and parents about life-threatening conditions before, during and after consultation

Principle	Detail	Challenges	Suggested Phrases
Prepare yourself	Examine your own comfort levels and beliefs. Use of supervision/ consultation as well as peer support can be invaluable. Ensure that when you meet the child, they can see you as a calm and focused person who is able to hear and tolerate their distress and provide emotional support.	Time limitations due to pressure of work. Managing your own distress about talking to the child about their illness. Managing your own experience of bereavement or loss.	
Prepare information	Plan what you need to communicate; prioritise key information. Check you know the name of the child and members of the family. Check relationships between the child and family (e.g. step parents).	Missing or inadequate information in child's health record.	"Is there anyone else who is important to you, who could be here to support you?" "My name is insert your name, can I just check I know everyone's name and who is here today?"
Prepare environment	Identify a quiet and private area. Consider who is with the child and who should be included in consultation, including relatives, advocates or other health-care professionals well known to child or family. Make arrangements to care for other siblings as appropriate, or if they are to be present, consider their needs (e.g. organising toys, colouring).	Availability of childcare for siblings to best support those taking part in conversation.	"Would it help if we found someone to look after your younger children while we talk?"

Development	Check the age of the child and any known neurodevelopmental problems or communication impairments. Consider child's understanding of language to be used in consultation (find interpreter if appropriate). Consider child's likely developmental understanding. Consider how to make information relevant to child's everyday context and culture. Choose developmentally appropriate language; accessible but not patronising. Consider use of universal communication tools - i.e. picture charts and things such as faces/symbols to gauge happy/sad/good/bad etc.	Facilities to support children with communication difficulties (e.g. deafness, blindness, and interpreters) may be limited or unavailable.	"How much do you feel your child understands about the world around them and about their condition/care?" "Are there any tools you use in communicating with your child that we could make use of in this conversation?"
Prepare the parents	Discuss with parents the importance of communicating with the child about the diagnosis.	Parent may be reluctant to involve child in consultation/wants to tell the child/assumes it is someone else's job to tell child.	"I wonder how much you think *insert child's name* knows about their health at the moment?" "Thinking about talking to *insert child's name* about this probably feels the hardest thing in the world. It's completely understandable to want to protect them from this news. But we do know that children are very good at picking up

			on changes around them, and helping children understand what is going on can help them feel less frightened and alone. It will also enable you to support them without having to pretend." "We are here to support you with this."
Build a relationship	Patients and parents value respect, trust and empathy. Use the child's name when talking to the child and family (ensures consultation feels personal despite being in a large hospital or busy clinic). Respect parents' and patients' existing knowledge around the condition, care or situation and treat them as an equal, respecting their own expertise in their personal lives and experiences.	Parents may share a different understanding of events or symptoms leading up to the consultation.	"Are there any questions that you feel are important for us to try and answer today?"
Listen first	Elicit the child and parents' story. Determine what the child knows already. Ask the child what they think is happening. Use this information to evaluate the child's level of autonomy and independence so that information can be directed accordingly, e.g. adolescents may want to take the lead in consultations. Children and adolescents should be given the opportunity to talk to the health-care	Acknowledge that child may not want to speak at that moment. A challenge when time-limited is to allow sufficient time to listen. Appreciate that some older children/young people talking on certain	"Tell me a little bit about what's been happening recently, leading up to being here today?" "Tell me what Mum or Dad told you about why we're meeting today?" "What do you know about what's happening

	professional alone to allow them to raise subjects they do not wish to share with their parents. Note: even older adolescents and young adults may appreciate the involvement of their parents in consultations.	topics may not want their parent(s) present. May need to use different approaches to conversations with different children. Children may lack confidence and/or self-advocacy skills.	to you? How do you feel about this?"
Language	Decide beforehand if you will name the life-threatening condition and consider implications of decision (consider age of child). Be consistent. Use clear language and avoid euphemisms or technical jargon. This prevents children feeling excluded or patronised by language they do not understand or feel is not tailored to them. Explain technical terms and jargon where necessary. After you have named the condition, stop for a few seconds to allow the family to take in what you have said. Then, sensitively check family's knowledge and understanding of the condition.	Parent or child may google name of diagnosis. Child may talk to peers e.g. in a ward setting.	"Have you heard of insert name of condition? What do you understand or know about insert name of condition?" "What name do you usually use for your condition?" "What do you already know about your condition?"
Information delivery in a timely fashion	Be honest and realistic.	Uncertainty may exist about prognosis (if so, acknowledge this). Children and their families vary in the	"Is there anything you would like me to expand on right now?" "Would you like to know everything in detail

		timescale over which they wish to receive information. Parents and children might want different amounts of information. Parents might feel very anxious about talking about prognosis in front of their child.	now? If not, how do you prefer to find out about things?”
Pace of information delivery	Provide simple, measured pieces of information. Pause to allow the family and child time to assimilate what you have said. Especially important after you name the diagnosis. Look for child/parents’ reactions to gauge when they are ready for more information. Communicate on child’s terms and with support from parents. Identify child’s priorities and tailor information accordingly e.g. some young people’s primary concern will be hair loss or whether hospital admission will interfere with a forthcoming social event, rather than treatment options.	Challenge is lack of cues from child or parents. Restrictions on time available for discussion. Be aware of emotional distress, fatigue or pain that may limit capacity to absorb information.	“Have you heard of *insert diagnosis* before?” If so, “What do you understand about *insert diagnosis*?” “Do I need to slow down? Would you like me to go over anything again?”
Sources of information	Provide visual as well as verbal information. Provide details of other sources of information (e.g. support group, useful websites or resources e.g.	Avoids information from unreliable websites or unhelpful social media.	“Would it help if I wrote down some of the things that we talked about today?”

	http://www.clicsargent.org.uk/content/storybooks-children http://healthtalk.org/content/talking-children-about-their-life-threatening-illness Honest answers Sound Advice: A Young person's Guide to Cancer www.teenagecancertrust.org). Give child information to take away. Consider options to connect with another family with similar experiences to help guide them through (based on family preference).		"Would a picture be helpful to understand what we talked about?" "Shall I show you some photographs to explain what I mean?" "Would it help to talk to someone else with a similar illness?"
Pay attention to emotional understanding	Follow the child's cues about their emotional understanding of the information. Allow child to express their feelings and explain these are normal in this situation.	Child's silence may indicate they have understood all or very little of the information. It is important to check with the child what they have understood. Possibility of misinterpretation of behaviour.	"Did you know many other children often feel very sad, confused or frightened; how do you feel about this? Is there anything you want to say?"
Acknowledge quantity of information given	Reassure the family that feelings of shock and distress are normal and make it very difficult to process information.	Religious, spiritual and cultural beliefs might need to be taken into consideration. Limited opportunities to talk to family again.	"Do you feel ready to hear some more about this now?" "Would you like me to write anything down for you?"

Ask child and parents what they have understood about what has been said	Check family are familiar with any medical terms used and whether there are local cultural meanings that need to be recognised. Try and gauge understanding of all involved to ensure no one is getting lost in the conversation. Check understanding throughout the conversation. If possible, ask the child what they understood. Provide parent and child with opportunity to ask questions. Reassure child and family there will be further opportunities to ask questions.	Important to ensure communication at correct developmental level. Some parents and young people are very familiar with medical language and procedures, whereas others are not.	"I know that it can be difficult to take this all in." "Is there anything you do not understand or would like me to explain further?" "Can I check how well I've explained things today? Would you like to tell me what you've understood so far?" "Some families find it helpful to write all their questions down and bring them to their next appointment."
Make a Plan	Explain to family what will happen next. Give family an idea of timescale for next steps, or, if unclear, when timescale will be clarified, including when their next appointment will be. Reassure families they will not have to manage this alone – if possible provide telephone/email contact details. If appropriate and/or available explain that symptoms can be controlled by medication, especially pain.	Challenges in resource-limited settings including lack of phones, difficulties attending health clinic appointments.	To the child: "You must let us know if anything hurts or feels funny." To the parent(s): "We know that you know your child inside and out. If you have any concerns, feel they are in pain or something is

	Consider other sources of support for family e.g. community health-care professionals. Communicate with other health-care professionals involved e.g. General Practitioner.		wrong, then don't hesitate to contact the team. We appreciate you are the expert in your child and we will always work with you."

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Authors' contributions

Alan Stein (AS) conceptualized and the designed the review. Louise Dalton (LD), Lucy Hanington (LH), Kim Fredman Stein (KFS) 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. Myra Bluebond-Langner (MBL), Sue Ziebland (SZ), Emily Harrop (EH), Ruth Bland (RB), Brenda Kelly (BK), Tamsen Rochat (TR) and KFS provided specific input to different 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 used to undertake 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, but in the context of evolutionary changes in healthcare philosophy around communication, different rates of change across HICs and LMICs, and gaps in the recent literature, we also included earlier studies and hand searched reference lists of papers selected (see Box 1 and 2 for search strategy and selection criteria). We focused on children and adolescents up to and including the age of 18 years, although a minority of studies in this review also include young adults. We have used the term children to refer to both children and adolescents and have specified the age range of participants within each study.

2. Expert Group Workshop 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 integrate the research literature and the theoretical 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 workshop 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 (http://healthtalk.org/content/talking-children-about-their-life-threatening-illness) along with focus group data from adolescents (12-18yrs) in the Together For Short Lives consultation commissioned by NICE. Following extensive discussion, core principles were derived to develop a framework. This was then further refined through consensus to create a series of guidelines. In this iterative process, information gaps were identified and future research direction discussed. The framework was also reviewed by a young adult who had cancer during their adolescence, and a young adult who has had an LTC since childhood.

BOX 1 - Search strategy and selection criteria

Data for this Review were identified using CINHAL (EBSCOHOst)[from 1982], Embase (OvidSP)[1974-2016 May 11], Medline(OvidSP)[from 1946], PsycINFO(OvidSP)[1967-April Week 1 2016], Science Citation Index & Social Science Citation Index(Web of Science Core Collection)[1945-2018]. 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, KFS and LD. Our final sample consisted of 57 articles from the search and 44 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 and adolescents about the diagnosis of their own Life Threatening Condition

Author	Qualitative or Quantitative	Size of study (n)	Type of participant	Child Age range in years (mean)	Child diagnosis	Method of recruitment	Method & measures	How was communication assessed?	Results	Location
Abadia-Barrero and Larusso 2006[57]	Qualitative	36	Children & adolescents; 18 HIV positive, 18 HIV negative, all of whom had lost one or more caregivers to HIV/AIDS	1-15	HIV positive & HIV negative	Support house that shelters children orphaned by HIV/AIDS	Open communication if words HIV/AIDS used. Participant observation & semi structured interviews	Qualitative analysis of interviews & observations	Children curious about their HIV/AIDS related experiences but most adults did not give direct explanations, or gave confusing or contradictory answers which inhibited children asking. Children's understanding of their difference based on taking/not taking medication. 7-9 year olds understand being sick & AIDS as negative, but are confused as to the relevance to their life. Preadolescents start to acquire knowledge about the disease but have many misunderstandings. Adolescents' growing awareness of the relationship between their lives & negative social values associated with HIV creates shame & anger. Adolescents with HIV have poor understanding of the implications of HIV for their lives & future risks to their health. Absence of support can result in inadvertent risk taking behaviour	Brazil
Adduci, Jankovic et al. 2012[33]	Mixed methods	128	64 children; 64 parents	4-18	Brain tumour	Neuro rehab unit (received treatment at least 1 year before). Children with psychological &	CBCL; VABS. Semi structured interviews with parents & children (separately)	Communication classified as: Avoidance (child did not receive any information or explanation about disease, or denial of	Significant relationship between the onset of internalising problems, withdrawal, anxiety-depression & social problems with the presence	Italy

						behavioural problems prior to onset of disease, & those who received psychological support at, or after diagnosis were excluded		disease & relevant treatment course); Ineffective (if only one of characteristics present – incomplete/untruthful/inconsistent/incomprehensible/discontinuous/impersonal); Effective (possess all 6 of complete/truthful/consistent/comprehensibe/continuous/personalised information	of avoidance of ineffective communication about the disease	
Arun, Singh et al. 2009[100]	Quantitative	50	Caregivers	Mean 8.98	HIV	HIV clinics	Structured interviews including questions about child's disclosure status, information given to child about disease & caregiver perceptions about disclosure. Care giver report children either aware, or unaware of HIV status	Caregiver report of child's awareness of HIV status	14% of children aware of their HIV status (according to caregiver report). 68% of children had been given no information, 26% told another diagnosis & 6% given factual information. Of the children on ART, 10% were told for HIV infection; majority of children told nothing or told for improving general health or other physical ailments. 44% of caregivers favoured HIV disclosure, with mid teenage as the appropriate age for disclosure	India
Badarau, Wangmo et al. 2015[71]	Qualitative	28	18 parents; 10 oncologists	8-18	Cancer (leukemia, lymphoma, CNS, sarcoma, other)	3 hospital cancer centres	Semi structured interviews including experiences of diagnosis & treatment, communication & decision making, attitudes to child involvement in healthcare	Thematic analysis	Parents reported too much information or high levels of emotional distress inhibited communication with child. Parents reported feeling unsure & unprepared about talking to child re diagnosis. Parents fearful information would cause child distress. Physicians highlighted tension between wanting to inform patient of diagnosis & implications, & desire of parents to withhold information	Romania

Bikaako-Kajura, Luyirika et al. 2006[55]	Qualitative	84	42 children taking ART; 42 primary caregivers	5-17 (median 12)	HIV	HIV clinics using selection matrix to include younger & older children who had & had not been disclosed to	Semi structured interviews including disclosure, adherence & associated challenges. Disclosure categorised as: Complete parental disclosure (both caregiver & child concur caregiver told child their HIV disease & medication); Non-disclosure (caregivers had not disclosed child's HIV status & report child does not suspect they are HIV positive); Partial disclosure (child not fully aware of HIV, but suspicious, asks Q of caregiver about disease & drug & in many cases assumes the drug is a cure, caregiver has postponed disclosure, lied during disclosure process or child learned of status from an external person or through overhearing conversations)	Disclosure status & coding of interviews	Complete disclosure & strong parental relationships related to good adherence. Children who had had full disclosure became self-motivated to adhere & were able to overcome external adherence challenges. As children became suspicious about their HIV status, ongoing lack of disclosure resulted in intentional non adherence by some children	Uganda
Binger, Ablin et al. 1969[87]	Qualitative	20 families	Bereaved parents	N/A	Leukaemia	Child's medical team	Semi structured interviews including details around diagnosis, relationships with	Content analysis	Parents appreciated HCPs' frankness & honesty about child's diagnosis & implications. Some families reported HCP became more	USA

							HCPs & short/long term impact on family		remote & avoided their child as death approached. Parents reported children aware of seriousness of their illness & anticipated death, even when not told. Adolescents who were aware did not experience greater difficulty than those who were naïve to their situation & parents reported more meaningful relationship as a result of honesty about the diagnosis. Patients tried to protect their parents from knowing they knew diagnosis. Authors suggest HCPs struggle with imminent death of patients & may avoid families actively or through "façade of busyness"	
Beima-Sofie, John-Stewart et al. 2014[90]	Qualitative	21	HCPs involved in care of HIV positive children	0-17	HIV	HCPs; selected to represent diverse array of settings.	Individual semi structured interviews including open ended questions about factors considered in decisions about whether to disclose diagnosis, barriers & strategies used	Thematic analysis & modified grounded theory	HCP experiences used to develop an experience-based framework to describe current disclosure practice. Providers had limited training but extensive experience in disclosure. Providers recognised importance of relationship between child & caregivers, considering caregiver concerns about disclosure, its timing & implications. Cited benefits of disclosure included importance for independence & autonomy, trust, preventing spread of infection, medical adherence & psychological health. Providers believe planed disclosure mitigated harm to the child from	Kenya

									overhearing their diagnosis & cited examples of negative impact on psychological wellbeing of children who discovered their diagnosis before deliberate disclosure. HCPs identified a number of factors that should be considered in terms of timing of a disclosure, including child's age, understanding, adherence & social situation	
Biadgilign, Deribew et al. 2011[78]	Quantitative	390	Caregivers of children with HIV receiving HAART	1-14 (median 8.5)	HIV	Child's medical team	Individual semi structured interviews including quality of healthcare services and diagnosis. Disclosure classified as 'disclosed' or 'not aware' of HIV status	Disclosure status	HIV status known by 17.4% of children in the study. 46% of respondents reported child should be told of their HIV status when older than 14 years old. Children aged under 9 & those living with educated caregivers less likely to know their HIV status. Children referred from the inpatient wards of the hospital before attending clinic & private clinic were more likely to know their status than those from community clinic. 60% of caregivers believed the doctor should be responsible for giving the child their diagnosis	Ethiopia
Blasini, Chantry et al. 2004[48]	Mixed methods	95	16 HCPs; 39 caregivers; 40 children	9->15(13.8)	HIV	Hospital HIV clinic & clinical trials unit	Quasi experimental study using specific model of disclosure for patient, family & staff members. Semi structured interviews & questionnaires (administered before & after disclosure). Educational cartoon	Disclosure status	Most patients had feelings of "normalcy" 6 months post disclosure & over half had improved their adherence to therapy after disclosure, as reported by patients & caregivers. 85% of patients & 97% of caregivers considered disclosure a positive event for themselves & their families. Fewer HCPs	Puerto Rico

							book about HIV given to child		reported feelings of fear, discomfort & insecurity after implementation of a disclosure model	
Bluebond-Langner 1989[21]	Qualitative	32	Parents; HCPs; children	3-9	Leukaemia, & other forms of cancer	Paediatric oncology outpatient clinics & inpatient admissions	Anthropological observation study, over 9 months. Modified form of play therapy with children to allow children to reflect on their own behaviour, in addition to a continued presence on the ward. Informal interviews with staff & parents of child patients	Anthropological observation and recording of children's conversations and play	Children had a greater understanding of their own illness & potential death than was appreciated by parents & HCPs	USA
Boon-Yasidhi, Naiwatanakul et al. 2016[49]	Quantitative	320	160 caregivers; 160 children	8-17	HIV	Medical team; HIV positive children who were not aware of their HIV status	Assessed psychosocial outcomes at baseline, before completion of a 4 step disclosure service, follow up assessment at 2 month & 6 months. Outcomes assessed using CDI, CBCL, PedsQL	Disclosure status	Small but significant reduction in median depression score between baseline & 2 & 6 month follow up following disclosure; small but significant increase in quality of life & social functioning domain scores. Reported behavioural problems did not change between time points	Thailand
Brown, Oladokun et al. 2011[56]	Quantitative	96	Caregivers	6-14 (8.8)	HIV	HIV clinic	Semi structured interviews including whether disclosure had happened & reasons for (non) disclosure. Disclosure classified as telling the child specifically that they have AIDS or a viral infection called HIV (caregiver report)	Disclosure status	13.5% of children had been disclosed to at mean age of 8.7 years. Disclosure prompted by children's questions about their illness, medication & needing to facilitate adherence. Main reasons for non-disclosure were: age of child, worries of psychological impact on the child & fear that child would blame parent. 63.5% of caregivers expressed a preference for disclosure by	Nigeria

									parents, while 14.6% preferred disclosure by parents & health workers together. In families where disclosure had taken place, caregivers for 7 of the 11 children felt adherence had improved	
Claflin and Barbarin 1991[69]	Mixed methods	43	Children	3-18	Cancer (leukaemia, lymphoma, non CNS tumour)	2 medical team	Semi structured interviews (including experiences of diagnosis & information shared about illness, treatment & prognosis, parental reaction) & likert scales	Analysis of interview responses	60% of children over 9 years had been told they had cancer; only 2 younger children had been told they had cancer. Children of all ages reported parental distress related to their condition	USA
Clarke, Davies et al. 2005[72]	Quantitative	55	Parents	3-18 (7.33)	ALL (4 months post diagnosis)	4 medical teams	Semi structured interviews (including views on what to tell their child & factors influencing their communication with child)	Thematic analysis	Distinguished four ways information conveyed by parents: optimism, realism, pessimism, factual. Four parental communication styles identified: minimal information, ambiguous information, factual information, full information. Parents disclosed more detailed & honest information to older children. Parents who believed ALL incurable gave children as little information as possible. Parents who felt too shocked & unable to grasp information more likely to tell child as much as they did understand themselves	UK
Cluver, Hodes et al. 2015[46]	Mixed methods	706	684 adolescents on ART (43 participate	10-19	HIV	39 health facilities traced adolescents who had ever initiated	Adherence measured by self-report PMAQ. HIV status defined as knows HIV status	Thematic analysis, adherence & disclosure status	70% of adolescents knew their HIV positive status. Knowledge of HIV status was associated with higher adherence, independently	South Africa

			d in qualitative study); 22 caregivers; HCPs (unspecified number)			ART to their communities	or does not know HIV status based on self-report		of all cofactors. Among perinatally infected adolescents who knew their status (n=362), disclosure prior to age 12 was associated with higher adherence. HCPs reported that disclosure was beneficial in reducing adolescents' perception of deception.	
Coyne, Amory et al. 2016[77]	Qualitative	82	20 children; 22 parents; 40 HCPs	7-16	Cancer (leukaemia, cancer of CNS, sarcomas, lymphomas)	Inpatient children's cancer unit	Semi structured interviews including experiences, views & preferences of information sharing & child involvement	Constant comparative procedure from grounded theory	Professionals advocated open & honest approach to information sharing; HCPs preferred to tell parents everything in order to fully include them in all information & treatment plans for their child. Some differences within HCP group in terms of how much information was shared with children & how. HCPs reported tailoring information to child's personality, cognitive ability, maturity & age. Used clinical experience to gauge a child's understanding & ability to cope with information. Parents wanted to manage how & when information shared with their children. Some parents felt information would negatively impact on their child's hope & spirit & wanted to protect their child. Some tension between HCPs & parents about extent to which parents 'filter' & interpret information. Children wanted to be included in information-sharing so they	Ireland

									were kept informed & felt prepared. Children valued their parents' role as interpreters of information, advocates, filters & communication buffers. Authors conclude HCPs need to be open minded, flexible and sensitive about familial preference for information-sharing strategies	
Dunsmore and Quine 1995[94]	Quantitative	51	Children & young adults	12-24	Cancer (ALL, CNS tumours & range of other cancers). 72% in remission, 20% receiving active treatment, 8% in relapse but no treatment.	Peer support group for cancer patients & siblings	42 item self-administered questionnaire including informational & psychosocial needs & preferences	Content analysis & coding of questionnaire responses	Participants wanted to be more informed about their illness & its implications & involved in treatment decisions. Almost all wanted to be informed about 'bad news'. Participants reported communication was facilitated by ability to listen, genuine concern, professional expertise & honesty. Study reports preferences about where & how information is communicated, & from whom they would like this information. Study highlights importance of a peer group who also have had experience of cancer	Australia
El Malla, Kreicbergs et al. 2013[63]	Quantitative	304	Parents	Not reported	Cancer	Child's medical team	Questionnaires developed by research team at two different treatment times. Topics included extent & manner information provided about disease, communication (interpersonal style of HCP & ability for patient & family to express thoughts &	Questionnaire	Parental trust in medical team associated with provision of adequate information, opportunity to communicate with physician, satisfaction with conversational style of physician, perception that physician sensitive to parent's emotional needs & that physician had met parents with care at start of treatment	Egypt

							concerns) & trust in HCP, psychosocial experiences in hospital			
Essig, Steiner et al. 2016[17]	Qualitative	54	30 HCPs; 16 former adolescent patients; 8 parents	13-19	Cancer survivors (disease free for at least 1 year)	Paediatric oncology clinics	11 Focus groups (separated by category of participant) including prompts to elicit experiences of good and poor communication, views on how HCP could communicate well	Inductive thematic analysis	Identified HCP, parent & patient perspectives on the factors that make communication difficult. HCPs & parents/patients focused on entirely different themes when discussing problems with communication (HCPs identified adolescents being withdraw & difficult, with other priorities; parents & patients highlighted specific needs of adolescents, experience of not being taken seriously, given too much or too little information) All 3 groups agreed communication is good when doctors honest & take their time. Paper identifies different expectations of communication from doctors & nurses (as rated by Drs, nurses & patients & parents)	Switzerland, Germany & Austria
Ferris, Burau et al. 2007[60]	Retrospective database analysis	325	Children	5-17 (13.5)	HIV	Child's medical team	Retrospective database analysis. 156 patients were disclosed to during duration of study; those disclosed to before midpoint of study categorised in disclosure yes' group; if in second half of study, categorised as disclosure 'no' group.	Disclosure status	Significant associations between not knowing HIV diagnosis & death, & not knowing the HIV diagnosis & disease progression	Romania

							CD4 cell count; number of days to death			
Fetzer, Mupenda et al. 2011[54]	Qualitative	40	20 children; 20 caregivers	8-17 (median 14)	HIV	Hospital HIV clinic (on ART for at least 6 months & had history of perceived poor adherence)	Caregiver confirmed child HIV status. Individual semi structured interviews including adherence experiences, barriers/facilitators to adherence & caregiver-child relationship	Qualitative content analysis	4 children aware of HIV status; were more compliant taking medicines & less conflict within child-caregiver relationship. None of the children regretted knowing their HIV status & reported their knowledge gave them 'strength' in medication adherence. Barriers to adherence included children feeling frustrated or fed up with medication regime & lack of adult supervision to support medication adherence. Lack of food to take with medication was a further barrier. Increased psychosocial support commonly cited as reason for good adherence, in addition to beliefs about helpfulness of medication. Discrepancies between child & caregiver reports of missed doses & adherence	DRC
Fortier, Batista et al. 2013[50]	Quantitative	240	120 children; 120 parents	8-18	Cancer - 41% leukaemia; other diagnoses of CNS cancer, lymphoma, sarcoma or other tumour.	Child's medical team	Parents completed: demographic information, Peds QoL. Children completed: PQ, STAI-ch, CUIS, Peds QL & cancer module	CUIS	Illness uncertainty prevalent; associated with lower quality of life (both general & cancer-specific) for both children diagnosed with cancer & parents. Illness uncertainty significant predictor of general health-related & cancer-related quality of life after controlling for children's age, pain & anxiety. Authors hypothesise that increased communication around a child's illness, expectation	USA

									around treatment & prognosis would decrease illness uncertainty & improve psychological outcomes for children	
Fritz, Williams et al. 1988[66]	Mixed methods	104	52 children; 52 parents	7-21	Cancer (2 years after completion of treatment)	Child's medical team	Structured interviews with patient & parents (separately) covering history prior to illness, illness & therapy course, detailed review of child's life since treatment ended. Parent interview also covered personal, social & occupational changes in their own lives consequent to child's cancer. Depressive symptomatology assessed by 2 independent ratings of CDRS, based on observation of survivor & interview content. Illness related data based on oncologists' ratings	Psychosocial variable *directness of communication* was derived from ratings of interviews. This variable was sum of ratings, on a 5 point scale of child & parents' responses to questions about how child handled illness in school & talked about It with peers, family & strangers. Survivors level of comfort about talking about illness was summarised in index of current openness, which included survivor's own assessment, parents' description & patterns observed during the interview	Direct communication during treatment explained a significant amount of the variance in school functioning, social/peer interaction, activity level, current openness & global adjustment. Communication patterns during treatment were most predictive of psychosocial outcome whereas indicators of medical severity were least predictive. Individuals who were rated as well adjusted used a range of different coping styles, with both "active approach" & avoidance being associated with good outcomes	USA
Gibson, Aldiss et al. 2010[67]	Qualitative	38	Children & adolescents	4-19	Cancer (47% ALL; others mixed cancer group)	Cancer treatment centres, posters & parent support groups. Purposive sampling to ensure mix of participants at specific stages on cancer journey	Age appropriate, participatory-based techniques including play & puppets & the draw & write method. Individual interviews & peer-interviews followed by group discussion, focus group & a	Inductive thematic analysis	Younger children reported being given information by their parents, whereas older children wanted to be spoken to directly by staff. Many older children felt they were not given enough information about illness & treatment & wanted this information directly from HCP. However also	UK

							written task for 13-15yr old age group. Questions & prompts used to elicit experiences of diagnosis, treatment & what had been helpful		important for HCP to recognise when adolescents didn't want to talk. Results used to model communication within a developmental context; suggests children (aged 4–12 years) reside in the background of information sharing with health professionals until they gain autonomy as young people (around age 13). They then move into the foreground, & parental role evolves to support from background	
Goldman & Christie 1993[82]	Quantitative	22	HCPs	4-16	Cancer	Patients treated in single oncology department who died during 1989	Questionnaire completed by HCPs after a child had died regarding perception of child's knowledge of death. Individual interviews with HCPs about their attitude to talking about death and how often they believed it occurred in the hospital.	HCP rated child's knowledge and categorised as: Open conversation: child discussed situation openly with family Acknowledged: child and family knew and knew each other knew, but didn't discuss it much Prevented: death not discussed by child, discussion was blocked by the family though the nurse felt that the child knew and wanted to talk. Not discussed: the death was not discussed by the child. The nurse felt that the child knew and chose not to talk. Ignorance: the death was not discussed by the child. The nurse felt that the child did not know	All staff members advocated on open, honest approach in talking to children about their death but varied widely and overestimated how often they believed discussion of the child's impending death occurred. Staff estimates of how many parents discussed death with their children suggest this was relatively infrequent, with only 3% having an open discussion and mutual acknowledgement between parent and child in a further 16%. Staff reported that this mirrored pre-existing patterns of honest communication between parents in these families.	UK

								Unknown: the nurse was not sure enough to designate.		
Haberer, Cook et al. 2011[53]	Quantitative	96	Children	Median age 6 years	HIV	Child's medical team	Disclosure status not reported. Adherence measured by electronic monitoring, unannounced monthly home visits for pill counts & caregiver report	Not measured	Average number of missed ART days lower for children who knew HIV status vs those who did not. Adherence worse when caregivers had good knowledge of why their child needed HIV medication, but may be explained by significant association between caregiver knowledge & another household member being on ART, reflecting households with greater HIV burden	Zambia
Jacobs, Perez et al. 2015[39]	Quantitative	34	17 children; 17 parents	14-21	47% leukaemia, 27% brain tumour, 20% solid tumour, 7% lymphoma	Family centred Advance care planning for Teens with Cancer study	31 item questionnaire (LACPS) administered orally by trained facilitators	LACPS	75% of adolescents believed it appropriate to discuss end of life decisions. 12% not comfortable discussing death. The majority of adolescents preferred to talk about death before facing end of life decisions. Understanding treatment choices was important for nearly all respondents. High levels of congruence within dyads about the importance of end of life issues, including "saying everything I want to people in my family", and understanding treatment choices. Adolescents wanted to be told if they were dying, but families were often not aware of this preference. Authors highlight the importance of facilitated discussions so that	USA

									caregivers are aware of adolescents' preferences	
Johnston and Appleby 2011[6]	Quantitative	52	Paediatric oncologists	N/A	Oncology	Survey of pediatric oncologists	Online survey of oncologists' experiences & opinions of breaking bad news	Survey responses	65% of respondents reported having at least some anxiety prior to disclosing bad news to families & patients. Respondents most concerned about how the patient or family would react, insufficient time & not having the answer to questions the family might ask. Variation in views about the age at which children should be included in the consultation, with most reporting that this should be assessed on a case by case basis	Canada
John-Stewart, Wariua et al. 2013[37]	Mixed methods	271	Caregivers	6-16	HIV	Child's medical team	Disclosure classified as: complete (sharing HIV specific information with child & naming virus as HIV); partial (providing child with nonspecific or incorrect health information regarding their infection & using explanations of other illnesses to account for clinic visits & medication); non disclosure (providing child with no explanation of their health condition). Individual semi structured interviews. Two focus group	Disclosure status and thematic analysis of focus group discussions	79% of caregivers reported children should be disclosed to, but only 19% of children had been told diagnosis. Caregivers of older children, who were HIV infected & had disclosed their own HIV status, or who travelled frequently, were more likely to have disclosed. Disclosure done primarily by HCPs (52%) & caregivers (33%)	Kenya

							discussions with subset of participants			
Kajubi, Whyte et al. 2016[45]	Qualitative	58	29 caregivers; 29 children on ART	8-17	HIV	Previous cross-sectional survey	Caregivers asked if they had explained what medicines were for; whether they had informed children what they were suffering from; if not, why not & when they intended to do so. Children asked about reasons they had been given for taking their medicines, who told them, what & how they were told, what they understood about illness Individual structured & semi structured interviews. Interviewers completed observations of child's interactions & communication with other family members during interview visit	Content thematic analysis	Tensions between the desires of caregivers & children regarding level communication about medicines. When caregivers withheld information which children wanted, children used strategies including medication refusal to try to elicit more information, & interpreted caregivers attempts to "protect" them from diagnosis as deception or betrayal	Uganda
Kreicbergs, Valdimarsdottir et al. 2004[62]	Quantitative	449	Parents	N/A	Cancer	Parents in Sweden who had lost a child to cancer between 1992 & 1997 directly contacted	Postal questionnaire (129 questions) including items relating to whether parent talked about death with child, child's awareness of death and parental reflection about	Questionnaire	None of the 147 parents who did not talk to their child about death regretted it. 69 of 258 parents who didn't talk to their child regretted not having done so. Parents who sensed their child was aware of impending death more often later regretted not	Sweden

							these decisions. Current parental anxiety & depression assessed using a 7-point visual digital scale		having talked with their child than the parents who did not feel their child had been aware of their approaching death	
Last and van Veldhuizen 1996[41]	Quantitative	112	56 children; 56 parents	8-16	Cancer	Child's medical team	Parents structured interviews about information they had given to their child. Children completed STAI-ch (Dutch version), DDQ, DSC, questionnaire about sources of information & ease of access to information	'Information about diagnosis' subscale: 5 items re seriousness, duration, medical terminology (tumour, growth, leukaemia), the term cancer & the possibility of a relapse or recurrence. 'Information about prognosis' subscale : 2 items about possibility child will not get better & possibility that child will die of the disease	Children who received open information about their diagnosis & prognosis at the initial stage of the disease showed significantly less anxiety & depression 3 months- 3 years later. Two thirds of children wanted to know everything about their disease & one third as little as possible. A quarter of children were ambivalent about what they wanted to know & answered questions inconsistently, which authors conclude reflects conflict about what children want to know	Netherlands
Lester, Chesney et al. 2002[44]	Mixed methods	100	49 caregivers; 51 children	4 & older	HIV	Child's medical team	Interviews with parents. Parent completed measures; BASC; LEQ, FRI, SSQ. Children measures; WPPSI-R/ WISC-R Children over 8 completed BASC. Disclosure classified as: no (HIV) disclosure (range of information from nothing to information about child's specific discrete infection/illness but without information about	Disclosure status	An earlier age of disclosure associated with higher child IQ & more family expressiveness. Factors associated with increased parental anxiety are HIV disclosure, other major life events, more frequent medication & child age	USA

							HIV or AIDS); HIV disclosure (information that child had HIV or AIDS diagnosis)			
Levenson, Pfefferbaum et al. 1982[96]	Quantitative	63	Adolescents	11-20 (15.8)	Cancer (leukaemia, lymphoma, bone/soft tissue tumour, organ tumour)	Child's medical team	Questionnaire developed by study team including items relating to participant report of current & preferred sources of information; preferences for receiving information	Questionnaire	Adolescents preferred information from HCP, with most wanting their parents included in discussions. Older adolescents wanted information through group discussions with similarly aged patients. New patients & those in relapse least receptive to additional information, tended to rely on parents rather than HCP. Hispanic patients' information needs poorly met; alternative ways of communication must be considered	USA
Lorenz, Grant et al. 2016[70]	Qualitative	28	Caregivers	0-14	HIV	Routine clinic visits, & had to have least one HIV-positive child who had been told their diagnosis & was receiving ARTs	Semi structured interviews including experiences & attitudes around HIV testing & disclosure to child	Thematic analysis	Majority of children were informed of HIV status between the ages of 5-9 (mean age = 7) all caregivers felt that a child who knew their HIV status would have a good attitude towards their medications. Nearly half had initially told the child they were sick with a disease other than HIV, citing concerns that the child was too young or unable to understand about HIV. Following disclosure, many caregivers were concerned about whether the child understood; this occurred across the full range of ages of disclosure. Caregivers expressed concerns about the psychological consequences of disclosure, causing	Uganda

									children feel that their life was" without hope"	
Mack, Wolfe et al. 2006[98]	Quantitative	214	194 parents; 20 HCPs	0.2-17.9	Cancer	Cancer Institute & Children's Hospital (30 days & 1 year from date of cancer diagnosis)	106-item parent questionnaire (63 previously validated questions). Information preferences assessed using items from ISQ & INQ. Communication process & trust in HCPs assessed using items from Picker Survey and TIP	Parents were asked if an oncologist had ever discussed their child's prognosis & whether this was expressed quantitatively. Prognosis was defined as whether child will be cured of cancer, life expectancy, the kind of life child can expect. Items from Picker survey to measure communication process	Almost all parents wanted as much information as possible about diagnosis, treatment & prognosis. 36% of parents found prognostic information extremely or very upsetting, but these parents still reported prognostic information was important. Parents were more likely to want additional information if they found information about prognosis to be upsetting. No evidence prognostic information had a negative impact on parents' sense of hope	USA
Mellins, Brackis-Cott et al. 2002[47]	Quantitative	154	77 caregivers; 77 children	3-13 (8)	HIV	HIV clinics	Caregiver rated child's knowledge of HIV status: definitely no; probably no; probably yes; definitely yes. Caregiver: Semi structured interviews about child's knowledge & experience of disclosure; CBCL, PCRI, STAI, BDI. Children: semi structured interviews about experience & emotional response to disclosure CDI, STAI	Disclosure status; communication subscale of PCRI	28% of children scored in clinical range on CBCL & 22% within the clinical range for depression. 30% of children 'definitely' or 'probably' knew their HIV status & had been told by their caregiver at an average age of 7 years. Knowledge of HIV status did not result in increased mental health problems. Child knowledge of HIV status was not associated with caregiver education, biological vs adoptive caregiving, PCRI or other socio-demographic variables	USA
Menon, Glazebrook et al. 2007[43]	Quantitative & sub group completed a	254	127 adolescent	11-15 (12.4)		HIV clinics	Disclosure criteria not reported but categorised as	Disclosure status and adolescent self-reported health problems	Compared to UK norms, participants had increased mental health problems	Zambia

	semi structured interview		s; 127 caregivers				disclosed, not disclosed or disclosure status unclear. Adolescents: SDQ; subset (n=38) interviewed about their views on attending a peer support group Caregivers: SDQ		(although this in part may reflect the absence of culturally appropriate normative data). 37.8% of adolescents had had their HIV status disclosed. Participants who had not had their HIV status disclosed were more likely to score in the abnormal range of the emotional difficulties subscale. Children were in favour of attending a support group with peers	
Merzel, VanDevanter et al. 2008[101]	Qualitative	14	Caregivers	10-16	HIV	Purposeful sampling of Northern Manhattan Adherence Initiative	Adherence defined as: complete adherence to the regimen during past 2 weeks based on client self-report and confirmation of strict adherence during interview. Semi structured interviews including communication, experience & attitude to healthcare/HCP	Inductive thematic analysis	Caregivers report positive effects of disclosure on motivating child to adhere to medication regimen, but most beneficial for children who were already cooperative or just beginning to question regimen. Disclosure not a strong adherence motivator for children who were described by caregivers as openly resisting medication; most aware of HIV status & parents reported no positive benefits of disclosure on adherence. Only 1 caregiver said they regretted telling the child	USA
Moodley, Myer et al. 2006[102]	Quantitative	174	Caregivers	0.4-11 (median 3.3)	HIV	HIV clinic	Disclosure defined as caregiver reported discussion of HIV with child. Semi structured interviews, questionnaire including open-ended questions about experiences or preferences of disclosure	Disclosure status. Descriptive analysis of open ended questionnaires and interview	9% of caregivers had spoken to child about HIV status (mean age =8.1 years); low rate of disclosure may reflect the young median age of children in the study. Of the caregivers who were also HIV-positive (73% of the overall sample) , those who had disclosed their status to child were more than 7 times more likely to have	South Africa

									talked to the child about the child’s HIV status. Reasons for disclosure included that the child has a right to know, reasons relating to the child’s mental health, & reasons relating to medication. Reasons for non-disclosure concerned fear that the child would tell others. Twelve-years given as the median preferred age for telling child they have HIV. Most caregivers (83%) reported best person to disclose would be the primary caregiver, although 16% would prefer a HCP to disclose	
Myer, Moodley et al 2006[99]	Qualitative	40	HCPs		HIV	HIV clinic	Semi structured interviews exploring attitudes and experiences around discussing HV with infected children	Thematic analysis of qualitative interviews	Most providers felt the optimal age for general discussions about an HIV + child’s health should start around age 6, but that specific discussions about HIV should be delayed until a median of 10 years. Most felt that caregivers should lead these discussions, but acknowledged that caregivers need support from HCPs.	South Africa
Oberdorfer, Puthanakit et al. 2006[79]	Quantitative	103	Caregivers	6-16 (9.5)	HIV	Hospital clinics	Cross sectional study using semi structured questionnaire including items relating to rationale & experience of (non) disclosure to child. Disclosure defined as caregiver’s perception of having told child about HIV	Disclosure status	30.1% of children knew their HIV status (although 47.1% of caregivers did not use the words HIV or AIDS). Mean age of disclosure 9.2 years. Reasons for disclosure included illness, HAART adherence & discrimination from school. Reasons against disclosure included fear of psychological consequences, child too young, & discrimination	Thailand

							diagnosis. Disclosure did not require using words HIV or AIDS. ‘Knowing’ group defined as children whose caregivers perceived child knew HIV/AIDS diagnosis; ‘Non Knowing’ group of children perceived by caregivers to be unaware of diagnosis.			
Rodriguez, Dunn et al. 2013[81]	Quantitative	188	94 mothers; 94 children	5-18 (10.4)	Cancer	Hospital clinic	Video-taped observation of mothers-child dyads talking about child’s cancer. Mothers: BDI-II	Mother-child communication coded at macro (IFIRS) & micro level (CCS)	Higher symptoms of depression were associated with lower positive communication & higher negative communication between mothers & their children	USA
Roscigno, Grant et al. 2013[97]	Qualitative	29	Parents	12-20 (16)	Severe traumatic brain injury	Early acute care locations (part of a larger study not specified)	Semi structured interviews about experiences from time of child’s injury to time of interview, including reported doctor-parent communication	Ethnography of Speaking: discourse analysis	Parents felt HCP forgot that impact of child’s injuries impaired parent’s ability to hear and assimilate information & prognosis. Limited time for questions & lack of information contributed to parental distress and uncertainty. Parents wanted clear explanations & honest information, including negative possibilities	USA
Santamaria, Dolezal et al. 2011[42]	Quantitative	392	196 caregivers; 196 children	8-16 (12.7)	HIV	Primary & tertiary care clinics providing family-centred care for families affected by HIV	Disclosure coded as: disclosed; not disclosed based on caregiver report. Children: CDI; STAI; SIS, questions about intention to disclose HIV status in different	Disclosure status	70% of participants had been told diagnosis (range 37% of 9-10yr olds to 90% of 13-14yr olds). Those who had been aware of their status for longer were more likely to report that they intended to disclose their status to sexual partners.	USA

							hypothetical situations Caregivers: CBCL		Children who knew diagnosis had significantly lower levels of anxiety compared to those who did not	
Sharkey, Lloyd et al. 2016[26]	Qualitative	30	15 parents; 25 HCPs	5-16	Paediatric inpatients with identified communication difficulties	Paediatric wards	Semi structured interviews with parents and HCPs; focus groups with HCPs. Topics included experiences of good and poor practice of communication with children who have a disability, involvement of parent and child in decisions and training needs.	Framework approach	HCPs and parents reported that time pressures often restricted communication with children, with questions directed to parents instead. Parents wanted their knowledge and expertise of communicating with their child recognised and utilised by HCPs. Both HCPs and parents emphasised the importance of trust and rapport in facilitating communication. HCPs were aware of communication aids but these were frequently out of date and rarely used.	UK
Sherman, Bonanno et al. 2000[61]	Quantitative	128	64 caregivers; 64 children	8-18 (11.8)	Long term survivors of HIV (diagnosed at least 8 years before recruitment to study) & half had contracted HIV through blood transfusions	Hospitals	Child reported disclosure to others assessed by closed question “Do your friends know you are HIV+?”. Interviews with child & caregiver (separately) approximately 1 year apart. Children: SPPC/A. Caregiver: CBCL	Child self-reported disclosure status to friends	Children who had disclosed their HIV status to friends over the 12month course of the study had a significantly larger increase in CD4% than children who had told their friends prior to the study or those who had not yet disclosed to friends. Self-disclosure did not impact on child’s behaviour or self-concept	USA
van der Geest, van den Heuvel-Eibrink et al. 2015[34]	Mixed methods	86	Parents	1-17	Cancer	Parents who lost a child to cancer (2000-2004) after receiving treatment at Children’s hospital	Postal Questionnaire including closed question about whether discussions about death took place with child and open ended questions about	Questionnaire. Framework approach to identifying emerging themes from open ended questions	55 parents did not discuss the impending death with their child. A number of themes identified in reasons given for not talking to their child: parents’ inability to discuss death, desire to protect child, views regarding talking with	Netherlands

							how they talked to child about death & their experiences of (not) doing so		children, parents' views of child characteristic, child's unwillingness to discuss subject, lack of opportunity, child's disability. The majority of parents felt positive regarding their decision about whether to talk with their child about their impending death or not. Authors recommend that HCPs should explore with parents whether they wish to talk to their child about death & identify parents' reasons that form the basis for their decision	
Vaz, Corneli et al. 2008[40]	Qualitative	40	19 children; 21 caregivers	10-21	HIV	Organisations providing care & support for children & families living with HIV	Semi structured interviews including reasons for disclosure, anticipated and actual responses to disclosure (caregivers); disclosure experiences& communication about health (children). Disclosure classified as adult caregiver or HCP using HIV, AIDS or (local synonymous word) with the child, specific to child's health status. Child had to state they had HIV, AIDS (or synonymous local term) during screening process	Disclosure status. Qualitative content analysis to identify themes & patterns	Reasons given for disclosure included child's adherence to treatment regime, need for child to "protect themselves or stay healthy" & the child's increasing age. Most caregivers used prayer before disclosure; other preparatory activities included talking to a HCP & planning responses to questions child might ask. Most children were surprised to learn of their diagnosis but 88% felt it was better for them to know their HIV status	DRC
Vaz, Eng et al. 2010[58]	Qualitative	16	8 caregivers; 8 children	8-17	HIV	Targeted recruitment from family-centred	Semi structured interviews with child (all aware of	Content analysis	Children described limited communication with their HCP prior to disclosure.	DRC

						HIV care & treatment program, based on program staffs' existing knowledge of children	HIV status) and caregiver (separately) including demographic & family characteristics; open questions about disclosure experiences, child's description & opinion of disclosure, understanding of HIV pre and post disclosure		Received little or misleading information from family about illness, medication & symptoms. On disclosure, children described feeling sadness, but also relief. Parents recounted children's reactions very differently	
Vaz, Maman et al. 2011[74]	Quantitative	201	Caregivers	5-17	HIV	Paediatric HIV programme	Structured interviews including emotional closeness between child & caregiver, patterns of disclosure & caregivers views of disclosure & stigma. Disclosure categorised as: No Information (questions about illness/ health ignored. Child told to take medications, attend appointments & avoid certain behaviours without reason being given); Deflecting information (information given not true, or would have to be retracted at a later date in order to provide other information, child	Disclosure category	Nearly 50% provided no information to child about their health; 33% had only given deflecting information about the child's health. 94% of caregivers felt child should be told HIV status & that they were the best person to tell them eventually. 75% had considered what might prompt them to disclose to child. 33% felt no benefits to telling child HIV status, citing concerns about psychological impact on child. Cited benefits of disclosure were improved self-care by child, child protecting themselves & others from harm	DRC

							told had another illness; Partial Information (HIV not mentioned, but given information that could provide some awareness of status, eg medications reduce incidence of symptoms, or that child is prone to falling ill. Child told to adopt preventative measures to avoid others getting sick); Mixed Information (combination of truth & deflection eg sick since birth, but don't have HIV)			
Vreeman, Scanlon et al. 2015[91]	Qualitative	84	61 caregivers who had & had not disclosed to their child; 23 HIV positive children who knew their status	10-16	HIV	Convenience sample recruited from HIV clinics	Focus group discussions, facilitated using semi structured interview guides including experiences & perspectives on HIV disclosure	Constant comparative analysis	Caregivers' decisions around disclosure influenced by a complex social environment including caregiver-child dyad, family members & wider social connections, schools, churches & media. Caregivers and children recognised stigma as a barrier to disclosure. Caregivers reported children had some awareness of their diagnosis before disclosure, which made disclosure more difficult as didn't know how much the child knew & when to start the disclosure process. Conversely, children generally denied knowing their status before they were directly told. Caregivers concerned	Kenya

									disclosure would harm the child psychologically, lead the child to blame the caregiver or disclose to other people	
Wolfe, Klar et al. 2000[64]	Quantitative	145	103 parents; 42 HCPs	10.8 at time of death	Cancer	Parents who lost a child to cancer (>1 yr previously mean 3.1 yrs) after receiving treatment at Children's hospital	Semi structured interviews with parents. Questionnaires with HCPs; medical notes review.	Categorical responses or Likert scales	There was a significant discrepancy between HCPs and parents' reported aware of when the child entered the end of life care period, with HCPs documenting this earlier in the illness. Smaller differences were reported when the child had a haematological malignancy, or their parents had no more than a high school education, or when a psychosocial clinician was involved in end of life care. Only 49% of parents reported that their understanding of no realistic cure for their child came from discussion with the medical team. Concordance between HCPs and parents' recognition that there was no cure for the child was significantly associated with earlier discussion of hospice involvement, better parental ratings of the quality of care delivered at home, earlier institution of 'do not resuscitate' orders and less cancer directed treatment in the last month of life.	USA
Woolley, Stein et al. 1989[95]	Quantitative	70	Parents	1-17	Cerebral degenerative disorder, brain tumour, Muscopolysa	Children's Hospice	Semi structured questionnaire including how diagnosis communicated, what parent liked	Parent rating of satisfaction with diagnostic experience & illness information	Parents valued an open sympathetic, direct, & uninterrupted discussion of the diagnosis in private. Time to absorb information and seek clarification from	UK

					ccharidosis, neuromuscular disease, other neoplasms		or disliked about how consultation managed & information provide. GHQ		HCP was important. Parents disliked evasive or unsympathetic brief interviews. With hindsight, no parent had wanted to be protected from bad news & consensus was that imagining the worst was worse than knowing it	
Woolley, Stein et al 1989.[85]	Quantitative	24	HCPs	N/A	Cerebral degenerative disorder, brain tumour, Muscopolysaccharidosis, neuromuscular disease, other neoplasms	Children's Hospice	Semi structured questionnaire including job satisfaction, factors that created and mitigated against stress, personal experiences, staff support and training. GHQ	Semi structured interview	25% of HCPs experienced high degrees of stress; these HCPs had experienced a recent personal bereavement or had previous bereavements that remained raw or unresolved. HCPs reported feeling undermined and distressed by the behaviour of some families, particularly when this was expressed as anger or criticism. Relationships difficulties within the HCP group were a further source of stress, with the authors highlighting the importance of staff support systems and cohesiveness. HCPs frequently reported the alleviation of suffering and distress in others as important to their job satisfaction.	UK
Young, Dixon-Woods et al. 2003[76]	Qualitative	32	13 children; 19 parents	8-17	Cancer or brain tumour	Paediatric oncology unit	Semi structured interviews about experience of communication about cancer	Constant comparative method	Period around diagnosis important in influencing patterns of communication, with parents managing what, when & how children told about illness. Parental roles could be problematic for young people, but many also actively utilised their parents to help manage communication. Communication preferences	UK

									based on personal preference rather than chronological age. HCPs need to be aware of dynamics between parents and young people which may lead to exclusion of young people’s voices & impede successful relationships with HCP	
Young, Ward et al. 2011[75]	Qualitative	53	Parents	1-12 (Median 4)	ALL	Six principal UK treatment centres	Semi structured interviews including experience of communication during child’s illness, relationships with HCPs & impact of illness on child	Constant comparative method & content analysis	Parents acknowledged benefits and challenges of joint meetings with HCP and children, including concurrent demands of childcare causing problems concentrating on the conversation, restricting communication with physicians & making emotional care of own child difficult. Authors suggest this could be addressed by separate meetings with parents before inclusion of the child, in order to allow parents time to absorb information	UK
Zwaanswijk, Tates et al. 2007[93]	Qualitative	36	7 children; 11 parents; 18 survivors of childhood cancer	8-17	Cancer	Consecutive inclusion in two university oncology wards	Online focus groups with prompts regarding experiences of diagnostic consultation, family and HCP roles around information exchange, preferences about decision making	Thematic analysis	Key aspects of interpersonal communication including honesty, support, need to be fully informed. Young patients wanted medical information & to be allowed to participate in medical decision making. Variations in preferences between participants & sometimes conflicting preferences between parents & patients. Emphasises the importance of idiosyncratic decisions about who, what , when of communication	Netherlands

Zwaanswijk, Tates et al. 2011[73]	Quantitative	144	34 children; 59 parents; 51 survivors of childhood cancer (age 10-30 at time of study)	8-17	Cancer	Consecutive inclusion from three paediatric oncology centres	Vignettes of hypothetical situations in which important factors were systematically varied were presented to participant following an experimental design. Participants asked to rate preferences regarding importance of affective communication of HCP, child's involvement in information exchange and decision-making for each scenario on VAS	Preferences rated on VAS	Empathy in relationship with HCP consistently rated as important by participants. In most situations participants preferred information to be given to the patient & parent simultaneously. Some variation in preference regarding the amount of information provided; mainly influenced by the hypothetical patient's age & emotionality. In most situations the participants preferred children to participate in medical decision-making	Netherlands

ALL: Acute lymphoblastic Leukaemia
ART: Antiretroviral Therapy
BASC: Behaviour Assessment Scale for Children
BSI: Brief symptom Inventory
CBCL: Child Behaviour Check List
CCS: Contingency Coding System
CDI: Children Depression Inventory
CDRS: Children's Depression Rating Scale
CHLoC: Children's Health Locus of Control
CNS: Central Nervous system
CSI: Coping Strategies Inventory
CUIS: Children's Uncertainty in Illness Scale
DDQ: Dutch Depression Questionnaire
DSC: Defence Scale for Children
FACES: Family Adaptability & Cohesion Evaluation Scale

FRI: Family relationship Index
GHQ: General Health Questionnaire
HAART: Highly Active Antiretroviral Therapy
HCP: Healthcare Professional
IES: Impact of Events Scale
IFIRS: Iowa Family Interaction Rating Scales
INQ: Information Needs Questionnaire
ISQ: Information Styles Questionnaire
LACPS: Lyon Advance care Planning Survey – Adolescent & Family Version
LEQ: Life Events Questionnaire
PCRI: Parent-Child Relationship Inventory
PedsQoL: Paediatric Quality of Life
PMAQ: patient medication Adherence Questionnaire
PTSDRI: Post-traumatic Stress Disorder Reaction Index
PQ: Pain Questionnaire
SDQ: Strength & Difficulties Questionnaire
SIS: Social Impact Scale
SNRDAT: Social Network Reciprocity & Dimensionality Assessment Too
SPPC/A: Self-perception Profile for Children/Adolescents
SSQ: Sarason Social Support Questionnaire
STAI: State-Trait Anxiety Inventory
STAI-Ch: State-Trait Anxiety Inventory for Children
TIP: Trust in Physicians Scale
TSC: Trauma Symptom Checklist
VABS: Vinel & Adaptive behaviour scales
VAS: Visual Analogue Scale
WISC: Weschler intelligence Scale for children
WPPSI: Weschler pre school & Primary Scale of intelligence

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