



Communication with children 1

Communication with children and adolescents about the diagnosis of their own life-threatening condition

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This is the first in a Series of two papers about communication with children about life-threatening conditions

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When a child is diagnosed with a life-threatening condition, one of the most challenging tasks facing health-care professionals is how to communicate this to the child, and to their parents or caregivers. Evidence-based guidelines are urgently needed for all health-care settings, from tertiary referral centres in high-income countries to resource limited environments in low-income and middle-income countries, where rates of child mortality are high. We place this Review in the context of children's developing understanding of illness and death. We review the effect 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 health-care 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.

Introduction

One of the most daunting challenges for a health-care professional or parent is to tell a child that they have a life-threatening condition. This scenario is not uncommon, with millions of children globally living with life-threatening conditions. An estimated 1·8 million children are infected with HIV,¹ and more than 300 000 children develop cancer each year.² In low-income and middle-income countries (LMICs) where the burden of disease is greatest, survival rates are often poor. Although more than 80% of children with cancer in high-income countries (HICs) now survive for more than 5 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 awareness will empower children and families to advocate for their care and treatment, which is especially important in LMICs, as highlighted by the recent *Lancet*

Commission which found that access to health care in this context is often unconscionably low.³

The moment that the diagnosis is conveyed is often remembered vividly for many years and is the beginning of a new trajectory for the family. Within some contexts, mainly in LMICs, some health-care professionals are often faced with life-threatening conditions and death, while for other health-care professionals it might be a relatively rare occurrence. Sensitive communication matters greatly to children and their families regardless of their life circumstances. Available recommendations from HICs have considered how to deliver 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 responsibility⁶ is sometimes avoided, in part through fear of how the child and their family might react.

Health-care philosophy about sharing information with children regarding their illness and prognosis has changed substantially over the past 70 years.⁷ Until the 1960s, prevailing practice was to withhold the diagnosis, or its life-threatening nature, to 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. 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 and

Search strategy and selection criteria

Data for this Review were identified using CINAHL (January, 1982–May, 2016), Embase (Jan 1, 1974–May 11, 2016), MEDLINE (January, 1946–May, 2016), PsycINFO (January, 1967–April, 2016), and Science Citation Index and Social Science Citation Index (1945–2016). We used a combination of keywords in title or abstract and subject headings for the following key concepts: children, communication, and life-threatening illness. 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.

parents or 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 health-care professionals might be limited, the transferability of these models is a challenge, particularly in over-burdened health systems.

In seeking to improve communication, health-care professionals and parents or caregivers alike must be aware of the cognitive, emotional, and psychological development of children and adolescents in relation to their understanding of death, and 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 a life-threatening condition

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 (panel 1).¹⁰

Children younger than 2 years have an awareness of object permanence and are developing a mental image of a parent or caregiver, becoming distressed when they leave and seeking their return. Children aged 3–4 years understand death as a departure, and part of the natural order of life, but when someone has died it is important for parents or caregivers to repeat the key message that the dead person will not, and cannot, return.¹¹ It is not typically until the age of 5–6 years that children understand the finality and irreversibility of death,¹⁰ although recent work suggests that some children might acquire this understanding 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 years 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 substantially influenced by what is known as magical thinking, between the ages of 4 years and 7 years.¹³ Magical thinking is used to describe children's belief that thoughts, events, or wishes can cause external events (eg, 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 (eg, illness is a punishment for their poor behaviour).¹¹ These concepts highlight the importance of ensuring that the language used with children is concrete and specific to avoid

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

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—ie, that there might be some form of personal continuation after death, such as the soul or spirit, which might be capable of life-like functions after death such as loving or helping.

Causality

Realistic understanding of events that might cause death.

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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 years 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 might 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 (eg, 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 might contribute to tension between the different priorities of patients and health-care professionals (eg, an adolescent's desire for independence and the health-care professional'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 because of the life-threatening condition. Adolescence also involves establishing autonomy from parents or caregivers, which might 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 life-threatening conditions 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 previous experiences and exposure to illness and death on their understanding of these concepts. Several case reports²⁰ and anthropological studies²¹ 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 scarce and inconsistent.^{24,25}

In the emotional turmoil of distressing news, children might 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. Although these children are more likely than those without disability to suffer substantial ill health, their communication needs are often poorly met in health-care settings²⁶ which might 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, and religious and spiritual beliefs will also influence children's and parents' or caregivers' perspectives on the meaning of death and illness (eg, possible reluctance in Catholic communities to disclose the life-threatening condition because it could preclude hope and faith).²⁹ Conceptual understandings of death vary widely worldwide (eg, a study in South Africa described how death can be seen as a transformational experience in which communication remains possible with deceased family members³⁰). The way these factors interact requires health-care professionals to explore an individual's belief system to ensure that the information communicated is meaningful, and to enable the health-care professional 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 life-threatening conditions involving children, and the absence of evidence-based guidelines to support health-care professionals and families to communicate the diagnosis, we aimed to address three main questions.

First, what is the effect of communication about a life-threatening condition on children and adolescents' emotional, behavioural, and social outcomes; and

illness-related factors including adherence to treatment, disease transmission, and progression? And what is the effect of the communication on their parents or caregivers and the wider family system? Second, what factors influence the process of communication and what are the barriers and challenges to communication? Third, what are the reported preferences of children, adolescents, and parents or caregivers on the way diagnostic information is conveyed?

The outcomes of the 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. The methods used are described in the appendix.

Findings of the Review

The results of this narrative Review are presented in relation to our three research questions; details of each study in the Review are summarised in the 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 (64 children aged 4–18 years) who had cancer showed that 12 of 64 children were not told about the disease.³³ In another study, 86 parents (64%) in the Netherlands did not discuss impending death with their child (1–17 years).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 (2977 children in total) describing patterns of HIV disclosure found that the proportion of children who knew their status was lower in LMICs (median 20.4%) than in "industrialised countries" (43%, mostly USA).³⁶ There might also be discrepancies between caregivers' beliefs about the importance of disclosing a diagnosis of HIV and their own disclosure practice. A survey of 271 caregivers of HIV-infected children (6–16 years) in Kenya found that 213 (79%) of 271 carers believed children should know their HIV status, although only 19% had disclosed the child's HIV status to them.³⁷ This finding highlights the importance of identifying the barriers that 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 17 adolescents (14–21 years) with cancer in the USA found that 13 (75%) of 17 adolescents 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 Republic of Congo explored the experiences and reactions of 19 children (10–21 years) to disclosure of

See Online for appendix

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

Effect of communication on 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 56 children (8–16 years) with cancer who received earlier information about their diagnosis and prognosis reported fewer symptoms of anxiety and depression compared with 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 and depression, and social problems, were significantly more infrequent when communication was classified as effective, as compared with avoidant or ineffective.³³ Retrospective reports from 86 parents whose children (n=56; 1–17 years) 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 effect of the disclosure of an HIV diagnosis on children's psychological wellbeing. A quantitative study in the USA of 196 children (8–16 years) with perinatally acquired HIV and their carers (n=196) found lower levels of anxiety in children who knew their HIV-positive status.⁴² 127 HIV-positive adolescents (11–15 years) in Zambia whose HIV status had not been disclosed were significantly more likely to score in the borderline or abnormal range for emotional difficulties than those who knew their diagnosis.⁴³ Delayed disclosure might have a negative effect, with children reporting feelings of anger and betrayal that they had not been told earlier.^{44,45} Health-care professionals in a South African study reported that 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

In a study of 77 children (3–13 years), it was found that the children might experience a range of emotions at the time of disclosure about their diagnosis including shock, sadness, anger, worry, and confusion, although these negative emotions did not always persist.⁴⁷ A group of 40 children in Puerto Rico (mean age 13·8 years), reported very low rates ($\leq 5\%$) of sadness, depression, and worry 6 months after disclosure of their HIV status, and 28 (70%) of 40 children described feelings of "normalcy".⁴⁸

A prospective, observational study of the psychosocial effect of a paediatric HIV disclosure programme in Thailand (n=160; 7–18 years) showed improved social

functioning at 6 months follow-up, in addition to a small but significant decrease in depressive symptoms.⁴⁹ Improved communication might alleviate uncertainty and consequently improve quality of life. Greater uncertainty about the illness and treatment in 120 children (8–18 years) 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 life-threatening conditions can have painful investigations and lengthy treatment regimens with unpleasant side-effects. Communication between the child, their parents or caregivers, and health-care professionals 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 684 adolescents (10–19 years) 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 of 96 children (median age 6 years) found that children who did not know their HIV status had poorer antiretroviral therapy adherence than those who knew their HIV status.⁵³ Improved medication adherence is consistently cited as a benefit of HIV status disclosure from several qualitative studies from the Republic of Congo, 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 that can lead to the transmission of HIV. Research in Brazil of 36 children (1–15 years) found that HIV-positive children had little communication about their diagnosis, resulting in a poor understanding of the risks of unprotected sex or donating blood for the adolescents in this group.⁵⁷ A qualitative study in the Republic of Congo of 8 children (8–17 years) reported that the children viewed the ability to protect others from infection as an important advantage of knowing their diagnosis.⁵⁸ In a study in the USA of 196 caregivers and children, children and adolescents (8–16 years) who had been aware of their HIV status for longer reported greater intention to disclose their status to sexual partners.⁴² Disclosure might actually prevent risky sexual behaviour because HIV-positive adolescents who were aware of their status were more likely to consistently use condoms than were unaffected peers.⁵⁹

A child's knowledge of their HIV status might have implications for the progression of their disease. A retrospective database analysis in Romania of 325 children (5–17 years) 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, than those who were aware of their HIV

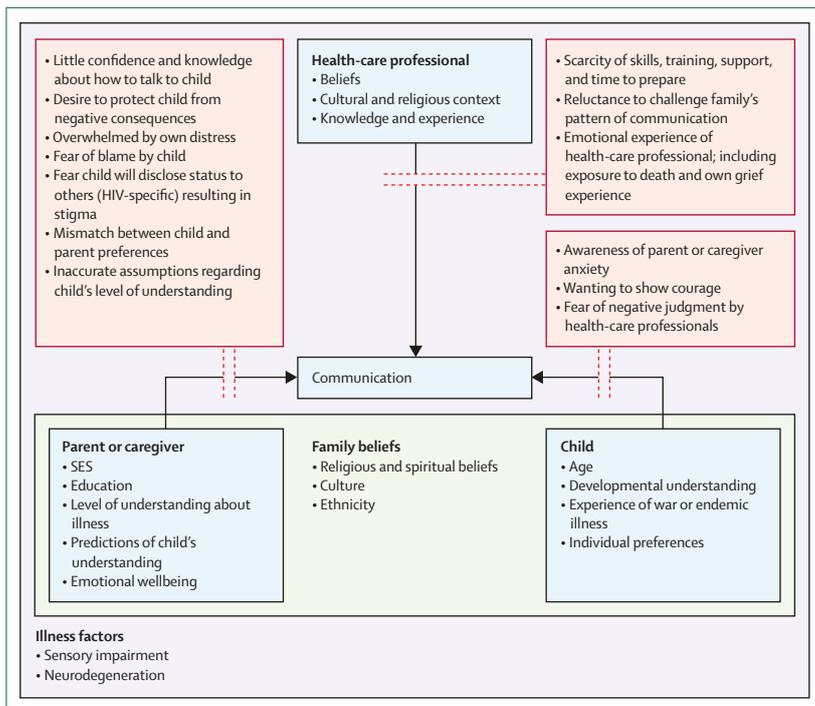


Figure: Factors influencing communication with children about their own life-threatening condition. Double red lines represent barriers to communication. SES=socioeconomic status.

diagnosis.⁶⁰ Evidence from the USA suggests that children (n=64; 8–18 years) 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

Effect of communication on parents or caregivers and the wider family system

Evaluation of a disclosure model for 40 paediatric patients with HIV (mean age 13.8 years) in Puerto Rico found that the disclosure process helped a large proportion of children and adolescents feel more supported by parents (58%), grandparents (48%), and clinic staff (48%).⁴⁸ 34 (85%) of the 40 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 or caregivers has also been explored. A retrospective Swedish survey of 449 bereaved parents whose children had died from cancer at least 4 years before the survey found that of the 147 parents who had talked to their child about death (a third of all participants), none regretted it.⁶² 69 (27%) of 258 parents who had not talked to their children, said they regretted their decision, and there were higher levels of current parental anxiety and depression within this subgroup.⁶²

A study of the communication between health-care professionals and 304 parents of children with cancer in Egypt showed important 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 103 parents whose children had died from cancer (mean age 10 years at death), found that a shared acknowledgment between health-care professionals 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

Factors affecting barriers and challenges to communication

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

Child factors

Although many children and adolescents want information about their illness, including discussions as to whether they might die, this is not universal, with estimates of a third to a quarter of adolescents not wanting this information.^{39,41,65} In a US mixed methods study of 52 survivors (aged 7–21 years) 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 limited understanding and awareness of their illness at the time had helped them to cope.⁶⁶

A retrospective study of 86 bereaved parents found that of those (n=55) that did not talk to their children (1–17 years; median age of 7 years at time of death) 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; 4–19 years) might 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 judgment from health-care professionals can also inhibit children's communication.⁶⁷

Child demographic factors

Parents and caregivers in several 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 a systematic review of paediatric HIV disclosure concluding that children between the ages of 10 years and 15 years are usually told their HIV status.⁵⁹ A quantitative study from the Republic of Congo of 201 caregivers of

children aged 5–17 years 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 64 children (4–18 years) 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 might underestimate younger children's understanding, which leads to information being omitted. Conversely, parents might overestimate older children's understanding and provide too much detail or at too complex a level.³³

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

Parental or caregiver factors

Parents or caregivers are often the interface between health-care professionals and the child or adolescent. Parents might adopt (or be delegated) a range of different roles^{71,72} in the communication triad^{75,76} which are dependent on several factors (panel 2).

Understanding, beliefs, and the response to information about a child's life-threatening condition

Parental communication is linked to parents' own understanding and emotional response to the diagnosis. A study of 55 UK-based parents of children (3–18 years) diagnosed with leukaemia explored the effect of parental perception of illness on the information they subsequently communicated to their children.⁷² Parents who believed that the life-threatening condition 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. By 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 might also reflect their own emotional distress and a desire to protect themselves from the "unbearable reality of the situation".⁶⁸

Panel 2: Roles parents and caregivers might take in the triadic exchange of information

- Facilitators of communication⁷⁶
- Envoys (acting as a go-between for patient and health-care professional)⁷⁶
- Human database (holding information to answer questions)⁷⁶
- Human buffers (using parents or caregivers to answer difficult questions)⁷⁶
- Communication brokers (to repeat or clarify information)⁷⁶
- Filtering and limiting upsetting information⁷⁷
- Confidantes (listening to children's private opinions)⁶⁷
- Allies (using language to support expression of preferences)⁶⁷
- Emotional safety and support⁶⁷

Parents might struggle to anticipate or react to worries their child might 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 Republic of Congo of 8 caregivers found that the caregivers were sometimes unaware that their children (n=8; 8–17 years) had outstanding questions or concerns after HIV disclosure.⁵⁸

There is variation in parental beliefs about talking to children about life-threatening conditions. A study of bereaved parents found that although 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 86 parents whose child had died 3–8 years previously, reported that 31 parents (36%) did discuss their child's impending death with them, of whom 24 (80%) of these parents reflected positively. Of those who did not talk about death with their child, 29 (60%) reflected positively. The authors conclude that parents need support making this decision.³⁴

Parental or caregiver education and sociodemographic background

Parental or caregiver educational level can influence communication, although the literature is inconsistent. A cross-sectional study of caregiver–child dyads in Ethiopia (n=390; 1–14 years) found higher rates of disclosure among caregivers who were illiterate than among caregivers with a higher educational level.⁷⁸ A similar finding was noted in a Thai study of 103 caregivers of HIV-infected children (6–16 years).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 than those of lower socioeconomic status.⁸⁰

Desire to protect child from distress

Parents or caregivers might not appreciate the potential importance of communication⁶⁸ 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 or 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 or 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 might also influence communication. A cross-sectional study of 94 children (5–18 years) with cancer and their mothers in the USA found that the mothers' symptoms of depression were associated with their observed communication style (eg, maintaining the same topic as the child, and 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 health-care professionals' communication

The health-care professionals' contribution to the triad of communication (child, parent or caregiver, and health-care professional) is also influenced by their own beliefs, cultural and religious context, experience, and knowledge, both at a professional and a personal level (figure). Barriers reported by health-care professionals 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 or 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 might affect a health-care professional'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 (eg, internalised responsibility to provide a "good death"); and feelings of depression, grief, and guilt in response to loss.⁸⁴ Frequent

exposure to death might activate the health-care professional's own memories of unresolved loss.⁸⁵ Health-care professionals can feel helpless that they were not able to prevent a child's death or spare the family emotional anguish.⁸⁵ The emotional effect of these issues can lead health-care professionals to feel ill-equipped to support children and their parents or caregivers, and could contribute to the high levels of psychological morbidity reported in UK clinicians (40% in 2002) and medical students.⁸⁶ Health-care professionals' strategies to manage their painful feelings in response to these challenging situations might 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 health-care professionals involved in palliative care have comparable levels of stress and burnout relative to colleagues in other specialities.⁸⁴ This finding might reflect service-related factors within palliative care, such as high-quality staff support which mitigates some of the stressors associated with working with dying patients.^{84,89} These observations indicate support structures are key for health-care professionals dealing with life-threatening conditions in different health-care contexts, but might only be aspirational in resource-constrained settings.

Differences in views, needs, and preferences within the triad

Health-care professionals and parents might have very different views about how much information should be shared with the child, often originating from the parents' desire to "protect their child".¹⁷ Although health-care professionals might advocate an "open and honest" approach to disclosure and information sharing, parents might disagree,⁷⁷ particularly around perinatally acquired HIV.^{90,91} Accurate information supports congruence between a child's internal world (ie, awareness of their illness, changes in their body, people's reactions, and possibly their imminent death) and their outer world (ie, information from parents and health-care professionals).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 might learn about their disease and how serious it is without being explicitly told.^{21,92} The parent and child might each attempt to protect the other from their own awareness of the disease by not acknowledging it. This "mutual pretence"⁷⁷ might 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 to not communicate; although 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

Panel 3: Summary of the preferences of children, adolescents, and parents or caregivers about the way diagnosis and information is conveyed

Preferences about how information is communicated

Relationship with health-care professional

Trust, honesty, and empathy of health-care professionals highlighted by qualitative studies of children, adolescents, and parents (child and adolescent patients,^{17,93,94} and parents^{93,95})

- Adolescents valued a professional-friendly relationship in which they felt the health-care professional was genuinely concerned and interested in them as an individual, rather than a collection of symptoms⁹³
- Respect within the relationship (adolescent report)
 - Demonstrated through the way staff recognise and negotiate an adolescent's priorities and competing demands (eg, maintaining social relationships around treatment)¹⁷
 - Communicated through sensitivity to cues that adolescents might not want to talk at a particular moment⁶⁷
 - Large ward rounds feel an invasion of privacy for adolescents; preference for separate discussions⁹⁴
- Respect within the relationship (parental report)
 - Facilitated by the doctor looking at them, greeting, and addressing them by name⁹⁵
 - Shown through recognising their parental role and being acknowledged as the experts about their child⁹³
 - Honesty extends to explicitly acknowledging the limits of professionals' knowledge⁹³
 - Importance of empathy, particularly in situations of poor prognosis, when parents have little experience of serious illness, or conversely, when parents work in health care and consequently hold substantial knowledge⁷³

Language

- Direct, clear, and as simple as possible^{73,94}
- Tailored to their particular age group (rather than "one size fits all")⁹³
- Balance between being understandable but not overly simple or "baby-ish"^{67,93}
- Avoid technical jargon; experienced by adolescents as an attempt to keep them powerless⁹⁴
- Straightforward approach, particularly around sensitive topics such as side-effects, prognosis, and fertility (sperm banking⁹⁴ or oocyte preservation)

Adequate time for consultation

- Enables information to be paced, questions answered, and clarification sought on both sides^{17,73,94}
- Parents, children, and adolescents recognise the effect of the initial shock of diagnosis; want time to come to terms with upsetting information⁹³
- Opportunity to ask questions; staff need to recognise that this is not always straightforward for children and adolescents, so they might need help to do so⁶⁷

- 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
- Some adolescents wanted discussions with health-care professionals without their parents present^{94,96}

Continuity of care

- Preference for consultations being with same health-care professional (where possible) throughout treatment (adolescents and parents)⁹³
- Consistency in the language and terms used⁹³
- Avoid potential miscommunication between health-care professionals or the need to repeat explanations or medical history to different health-care professionals⁹³

Sources of information

- Increasing dominance of adolescents' wider social network reflected in adolescents' reports of their preferred sources of information about their illness (eg, adolescents with cancer preferred to discuss cancer with their health-care professional first, followed by another teenager with cancer, and finally their parents⁹⁴); questionnaire surveys of adolescents with cancer indicating a preference for greater direct involvement with health-care professionals in adolescence⁹⁶

Location of conversations

- Parents' strong dislike of having prognostic discussions in earshot of their unconscious child as they felt concerned that "negative talk" might adversely affect their child⁹⁷

Preferences about what information is communicated

Information about illness and treatment

- Parents acknowledge the effect of the shock on their ability to understand and retain information⁹⁵
- Importance of checking understanding, repeating information, offering early follow-up, and written information^{93,95}
- Information about immediate and long-term future⁹⁴
- 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}

Prognosis

- Parents want as much information as possible; understanding of prognosis explained carefully in terms of likely timescale of events and providing detail of survival statistics⁹⁸ (when this is not possible or available, parents wish to have the limits of available information and uncertainty acknowledged⁹⁷)
 - Prognostic information very helpful in maintaining hope regardless of their child's prognosis⁹⁸

(Continues on next page)

(Panel 3 continued from previous page)

- 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 because health-care professionals might consciously or unconsciously tailor information on the basis of the reaction of the parent⁹⁸

Decision making

- Families felt their decision making was supported by honesty, trust, being given time to decide, discussions of risks, and benefits and understanding choices⁸³

Preferences about who should be involved in communication

Age

- Consensus towards greater inclusion of children in consultations with increasing age⁵

Presence of child

- Parental reservations about the child being present include feeling unable to ask specific questions around prognosis and being concerned about the potential emotional effect 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 treatment⁷⁵

- Parents, particularly mothers, of younger children sometimes feel distracted by their child's demands while trying to attend to the medical consultation⁷⁵
- Cultural and contextual differences in expectations of who should talk to the child about their illness
 - In some settings health-care professionals 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 child⁷⁸
 - Caregivers of children with HIV in the USA valued discussions with health-care professionals to prepare for conversations with their child about the diagnosis and often cited the health-care professional as the most appropriate person to talk to their child¹⁰¹
 - A South African study found parental or caregiver discussion about disclosure with a health-care professional was associated with disclosure to the child; 96% of parents or caregivers who had not discussed disclosure with a health-care professional reported that they would like to talk to a health-care professional about disclosure¹⁰²

be revisited. Increasing autonomy during adolescence can also result in parents or caregivers and adolescents holding contrasting views about treatment decisions. These situations are both ethically and emotionally challenging for health-care professionals, especially if the health-care professional has a strong opinion themselves.¹⁷

Reported preferences about how diagnosis and information is conveyed

Studies have investigated the preferences of parents or caregivers and children regarding what and how diagnostic information is communicated (panel 3). Most participants were adolescents with cancer, predominantly from HICs, but their views offer invaluable practical guidance for health-care professionals which might be applicable across multiple health-care settings.

Ethical and moral arguments are pertinent to communication with children with life-threatening conditions. 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 of diagnoses because children's understanding of their own condition is important to obtain assent or 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 while 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 life-threatening conditions in HICs and LMICs met for a two-day workshop in Oxford, UK, in 2017. The group used the outcome of the literature review and 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 health-care professionals in communicating with families (table). These are guiding principles; it is not expected that every principle applies to every situation and each health-care professional should also use their clinical skill and judgment 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—eg, in an acute situation the child and parent or caregiver might be unable to assimilate large quantities of information (because of physical symptoms such as fatigue or pain, and emotional distress). Key messages must be prioritised, repeated, and checked for understanding.

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 life-threatening conditions 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 or comparison groups, which makes evaluation of the effect of communication difficult. There is almost a complete lack of adequately powered, controlled evaluation studies, especially randomised controlled

| | Detail | Challenges | Suggested phrases |
|----------------------|---|---|---|
| Prepare yourself | Examine your own comfort levels and beliefs. Use of supervision or consultation and 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 own distress about talking to the child about their illness. Managing 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 (eg, 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 <i>insert your name</i> , 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 (eg, organising toys or 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—ie, picture charts and things such as faces or symbols to gauge happy, sad, good, bad, etc. | Facilities to support children with communication difficulties (eg, deafness, blindness, and interpreters) might be limited or unavailable. | "How much do you feel your child understands about the world around them and about their condition and 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 might be reluctant to involve child in consultation, or wants to tell the child or assumes it is someone else's job to tell the child. | "I wonder how much you think <i>insert child's name</i> knows about their health at the moment?" "Thinking about talking to <i>insert child's name</i> 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 might 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—eg, adolescents might want to take the lead in consultations. Children and adolescents should be given the opportunity to talk to the health-care professional alone to allow them to raise subjects they do not wish to share with their parents. Note that even older adolescents and young adults might appreciate the involvement of their parents in consultations. | Acknowledge that child might not want to speak at that moment. A challenge when time-limited is to allow sufficient time to listen. Appreciate that some older children and young people talking on certain topics might not want their parent(s) present. Might need to use different approaches to conversations with different children. Children might have little confidence and self-advocacy skills. | "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 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 the family's knowledge and understanding of the condition. | Parent or child might Google name of diagnosis. Child might talk to peers—eg, in a ward setting. | "Have you heard of <i>insert name of condition</i> ?" What do you understand or know about <i>insert name of condition</i> ?" "What name do you usually use for your condition?" "What do you already know about your condition?" |

(Table continues on next page)

| Detail | Challenges | Suggested phrases |
|--|--|--|
| (Continued from previous page) | | |
| Information delivery in a timely fashion | Be honest and realistic. | Uncertainty might exist about prognosis (if so, acknowledge this uncertainty). Children and their families vary in the 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. |
| Pace of information delivery | Provide simple, measured pieces of information. Allow the family and child time to assimilate what you have said, especially important after you name the diagnosis. Look for child or 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—eg, 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. | Uncertainty might exist about prognosis (if so, acknowledge this uncertainty). Children and their families vary in the 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. |
| Sources of information | Provide visual and verbal information. Provide details of other sources of information (eg, support group, useful websites or resources. ¹⁰⁵⁻¹⁰⁷ Give child information to take away. Consider options to connect with another family with similar experiences to help to guide them through (based on family preference). | Avoiding information from unreliable websites or unhelpful social media. |
| 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 might indicate that 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. |
| 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. |
| Ask child and parents what they have understood about what has been said | Check if the family are familiar with any medical terms used and whether there are local or cultural meanings that need to be recognised. Try to 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. |
| 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 and email contact details. If appropriate or available explain that symptoms can be controlled by medication, especially pain. Consider other sources of support for family—eg, community health-care professionals. Communicate with other health-care professionals involved—eg general practitioner. | Challenges in resource-limited settings including absence of phones and difficulties attending health clinic appointments. |
| | | <p>"Is there anything you would like me to expand on right now?"</p> <p>"Would you like to know everything in detail now? If not, how do you prefer to find out about things?"</p> <p>"Have you heard of <i>insert diagnosis</i> before?"</p> <p>If so, "What do you understand about <i>insert diagnosis</i>?"</p> <p>"Do I need to slow down? Would you like me to go over anything again?"</p> <p>"Would it help if I wrote down some of the things that we talked about today?"</p> <p>"Would a picture be helpful to understand what we talked about?"</p> <p>"Shall I show you some photographs to explain what I mean?"</p> <p>"Would it help to talk to someone else with a similar illness?"</p> <p>"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?"</p> <p>"Do you feel ready to hear some more about this now?"</p> <p>"Would you like me to write anything down for you?"</p> <p>"I know that it can be difficult to take this all in."</p> <p>"Is there anything you do not understand or would like me to explain further?"</p> <p>"Can I check how well I've explained things today? Would you like to tell me what you've understood so far?"</p> <p>"Some families find it helpful to write all their questions down and bring them to their next appointment."</p> <p>To the child:</p> <p>"You must let us know if anything hurts or feels funny."</p> <p>To the parent(s):</p> <p>"We know that you know your child inside and out. If you have any concerns, feel they are in pain or something is 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."</p> |

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

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 or caregiver or health-care professional. Moreover, the informational or emotional content and developmental appropriateness of the communication is rarely specified

or evaluated. This omission should be addressed in future research.

It might be perceived as difficult to initiate research at such a vulnerable time in a family's life, with ethics committees and staff protective of this patient group. However, research with 69 bereaved parents indicated that although many were initially motivated by altruistic reasons to take part in research, participants subsequently reflected that they had found it personally helpful.¹⁰⁸

Research should therefore consider how to sensitively involve children and parents or caregivers in studies 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 life-threatening conditions, or children with acute life-threatening conditions. Globally, most children live in LMICs and more research must be devoted to their health-care needs, and the 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 affect children in the extended family, particularly siblings who might have differing developmental needs. The framework of principles (table) could be useful for siblings, but further work is required. Parents' or caregivers' and children's increasing ability to access information independently through the internet creates both opportunities and challenges that affects the communication relationship with health-care professionals. Communication skills are a key component of training curricula for health-care professionals, but the effect of such training on clinical practice has rarely been evaluated,⁴ or the barriers which impede implementation identified.⁴ Extensive communication skills training and ongoing support programmes are required in both LMICs and HICs.

Communicating the diagnosis of a life-threatening condition 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 long-term communicative relationship between the health-care professional, parents or caregivers, and child.¹⁰⁹ Effective communication requires an understanding of how the parent or caregiver and child perceive the situation, the transfer of information, and also emotional support for parents, caregivers, and families. Providing emotional support to families is time-consuming and undoubtedly has an effect on health-care professionals; support to process the personal effect of this work is crucial to ensure that health-care professionals are able to cope with the emotional demands of this work.

Contributors

AS conceptualised and designed the Review. LD, LH, KFS, and AS undertook the literature searches and selected the studies. AS, LD and ER gathered the information from the studies and drafted the manuscript. MB-L, SZ, EH, RB, BK, TR, and KFS provided specific input to different sections of the manuscript; the 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.

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Declaration of interests

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 competing interests.

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