



## Communication with children 2

# Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent

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

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Many adults diagnosed with a life-threatening condition have children living at home; they and their partners face the dual challenge of coping with the diagnosis while trying to maintain a parenting role. Parents are often uncertain about how, when, and what to tell their children about the condition, and are fearful of the effect on their family. There is evidence that children are often aware that something is seriously wrong and want honest information. Health-care professionals have a key role in supporting and guiding parents and caregivers to communicate with their children about the diagnosis. However, the practical and emotional challenges of communicating with families are compounded by a scarcity of evidence-based guidelines. This Review considers children's awareness and understanding of their parents' condition, the effect of communication around parental life-threatening condition on their wellbeing, factors that influence communication, and the challenges to achieving effective communication. Children's and parents' preferences about communication are outlined. An expert workshop was convened to generate principles for health-care professionals, intended as practical guidance in the current absence of empirically derived guidelines.

## Introduction

Many adults diagnosed with a life-threatening condition are parents with children living at home. In the USA alone, it is estimated that 2·85 million children (18 years or younger) are living with a parent who has been diagnosed with cancer.<sup>1</sup> In low-income and middle-income countries (LMICs) life-threatening conditions affect even more families; WHO estimates that 70% of deaths from cancer worldwide occur in LMICs.<sup>2</sup> Life-threatening infections such as HIV are also more common in LMICs, with sub-Saharan Africa the most severely affected with nearly one in every 25 adults living with HIV.<sup>3</sup> In parts of Southern Africa over a quarter of pregnant women are HIV-positive.<sup>3</sup> With Prevention of Mother to Child Transmission programmes,<sup>4</sup> the vast majority of their children are HIV-negative but are born into families where at least one parent is HIV-positive. Although treatment advances for HIV have markedly improved long-term prognosis, daily medication and

frequent clinic appointments are still required. Furthermore, over one million people died of HIV in 2016, largely because of limited access to adequate treatment.<sup>4</sup>

Parental life-threatening conditions have an effect on the physical, social, and emotional wellbeing of children. A large cohort study of over 60 000 children in Finland found significantly higher use of psychiatric services by children who had been affected by parental cancer before the age of 21 years than in those who had not been affected.<sup>5</sup> In low-income settings, parental illness or death can even affect child survival; in rural South Africa the risk of mortality for children under 5 years increased both after their mother had died and in the months before her death.<sup>6</sup> Parents with life-threatening conditions face the dual challenge of coping with their diagnosis and treatment, while maintaining their caregiving role. Parents might feel unsure about how to talk to their child and how much information to share with them, while also wanting to protect their child from distress. Parents would benefit from clear guidance and support from health-care professionals about how to approach these topics with their children. However, when a parent is ill, the health-care professionals involved are primarily focussed on the adult patient. They might never have direct contact with the patient's children or be aware of the effect of the illness on the wider family. Indeed, many might be unsure about whether considering the needs of the patient's children forms part of their role. It can be difficult for health-care professionals treating adults to raise the issue of children's understanding of parental illness and the importance of communicating with them about the illness; this challenge can deny parents

## Search strategy and selection criteria

Data for this Review were identified using CINHALL (January, 1982–May, 2016), Embase (Jan 1, 1974–May 11, 2016), MEDLINE (January, 1946–May, 2016), PsycINFO (January, 1967–April, 2016), Science Citation Index and Social Science Citation Index (January, 1945–May, 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, and we applied a search filter to identify systematic reviews of qualitative studies. Commentary, letters, conference abstracts, dissertations, and case reports were excluded (appendix). 5427 records were identified of which 2132 were duplicates. 2281 potentially relevant articles and reviews were reviewed by LH and LD. Our final sample consisted of 43 articles from the search and an additional 34 articles identified from references of relevant articles.

much needed resources and support. Empirically based, parent or caregiver-focused recommendations are largely scarce,<sup>7</sup> making this emotionally challenging task especially difficult for health-care professionals.

### Aim of the review

Given the scale of the global burden of life-threatening conditions affecting parents, and the absence of evidence-based guidelines to support health-care professionals and families to communicate the diagnosis to children, we aimed to address four main questions. First, what is the evidence that communication with children about parental life-threatening conditions is important? Second, what is the effect of communication on children and adolescents' emotional, behavioural, and health outcomes? And what is the effect of communication on parents and the wider family system? Third, what factors influence the process of communication? And what are the barriers and challenges to communication? Fourth, what are the reported preferences of children, adolescents, and parents about the way that diagnosis and information is conveyed?

The outcomes of this Review and previously published recommendations<sup>8</sup> formed the basis of discussion at a workshop of international experts in 2017 to generate a framework of communication principles to address the scarcity of evidence based guidelines. The methods used are described in the appendix.

### Findings of the Review

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

### Why communicating with children about parental life-threatening conditions matters

The literature identifies several compelling reasons to encourage parents, supported by health-care professionals, to discuss their illness openly with their children. Children are very observant and might notice their parents' physical deterioration, or be aware that their parent is taking medication, or that their parent is going to a clinic. A Chinese quantitative survey of 626 children (aged 6–17 years) found that less than 40%

of the children (150 of 491 children for fathers with HIV, and 198 of 511 children for mothers with HIV) heard about their parents' HIV status from the parents themselves, yet of those who were not told by their parents, over 80% (290 of 341 children for fathers with HIV, and 257 of 313 children for mothers with HIV) were aware of their parents' diagnosis or illness through their own observations or from other people.<sup>9</sup> In Botswana, a study of 32 children aged 5–18 years showed that a third of parents who were HIV-positive thought that their child had guessed their HIV-positive status.<sup>10</sup> A qualitative study of 56 Zimbabwean orphans aged 7–22 years found that many bereaved adolescents partially knew, or strongly suspected, that their parents were HIV-positive although few had been formally told.<sup>11</sup> Children often felt unable to ask about the changes they had noticed in their parents with HIV, leading to tension and anxiety.<sup>12</sup> A qualitative study of 28 children aged 3–18 years in the USA reported that even young children showed an awareness of their parent's medical condition (eg, a 3 year old child drawing pictures of her mother with and without hair following chemotherapy) and its implications.<sup>13</sup> A UK-based qualitative study of 37 mothers with breast cancer and their children (n=31; 6–18 years) found that some of the younger children (6 years) were aware of cancer as a life-threatening condition and had suspected something was seriously wrong before they were told the diagnosis.<sup>14</sup>

Research consistently highlights the need for communication with children in a timely manner and the potential negative consequences when information is absent. A quantitative study in Sweden of 622 young adults aged 13–16 years that had been bereaved for 6–9 years earlier during their adolescence found that 595 (98%) of 610 young adults thought that teenage children should be informed when their parents' death was imminent, although only 367 (59%) of 617 young adults had themselves been told.<sup>15</sup> A qualitative study in the UK of 33 adults who had experienced the death of a parent during childhood (13 months–17 years), reported that their distress had been compounded by a paucity of accurate information about their parent's death.<sup>16</sup> A Danish qualitative study involving parents with cancer and their children (21 children aged 8–15 years from 15 families), reported that with the benefit of hindsight, parents who had allowed some time to elapse before disclosing their diagnosis regretted this decision and felt that their children had reacted negatively to not being told earlier.<sup>17</sup>

When children are not given information about their parent's illness, they attempt to make sense of the situation on their own. Children's beliefs can be "more dire than the truth" and it is essential to dispel misconceptions and magical thinking.<sup>18–20</sup> Clear communication can help children to prepare for changes or loss, enabling them to receive support.<sup>21</sup> An absence of

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See Online for appendix

information might result in consequences. Misinterpretation of parental symptoms such as hair loss and other side-effects of treatment can be wrongly interpreted as deterioration in their parent's condition, and adequate explanation can provide reassurance.<sup>22,23</sup> Additionally, children rely on their own observations to construct their reality; in a Ugandan study, adolescents (13–19 years) who were not told that their parent had died of HIV or AIDS, attributed the death to either a treatable condition or a spiritual cause.<sup>24</sup> This absence of information might lead to children worrying that they have caused the illness.<sup>14,19,25</sup> In a US study, 87 children aged 7–11 years attempted to understand their parent's illness through links with unrelated events.<sup>19</sup> 11 bereaved adolescents (13–18 years) in another US study reported that insufficient or distorted information resulted in feelings of regret and guilt about their possible role in causing or failing to prevent the death.<sup>26</sup> Also, children worry about their own health and risk of developing a similar condition.<sup>14,19,25</sup>

### Effect of communication on children and adolescents' emotional, behavioural, and health outcomes

Research has explored the relation between communication about a parent's illness and children's psychological symptoms, with many studies indicating the benefits of communication for children. A longitudinal study in the USA assessed outcomes for mothers who were HIV-positive and their children who were HIV-negative (135 children aged 6–11 years).<sup>12</sup> During the study some mothers disclosed their HIV status to their children. Analyses indicated a trend towards lower anxiety and a significant decrease in symptoms of depression in the children following maternal disclosure.<sup>12</sup> Children whose mothers disclosed their diagnosis also reported lower levels of negative self-esteem (child-reported)<sup>27</sup> and lower levels of aggressiveness (maternal report)<sup>12</sup> compared with children of non-disclosing mothers.

Positive family relationships were associated with lower anxiety and depression in 50 adolescents aged 12–19 years whose parent had cancer in a US study.<sup>28</sup> The relation between anxiety and family cohesion was mediated by the extent to which family members expressed their thoughts and feelings (adolescent-report).<sup>28</sup> A quantitative study in the UK of 56 adolescents (11–17 years) and their mothers with early stage breast cancer found that adolescents had higher total problem scores when compared with published norms, for both internalising symptoms (anxiety or depression symptoms, or both) and externalising behaviours, that were significantly associated with poor communication generally.<sup>29</sup> A mixed methods study of 44 children (6–16 years) in Israel found that those who had been explicitly told that their parent had cancer and its serious nature had significantly lower levels of anxiety than those who had not been told.<sup>30</sup>

A Dutch quantitative study of 284 adolescents and young adults (11–23 years) who had a parent with cancer found a significant association between daughter's levels of stress and their perception of the seriousness of their parent's illness.<sup>31</sup> This association was not found for sons.<sup>31</sup> This study did not compare children's perceptions of seriousness to clinical ratings of disease severity, but concluded that it is important to ensure children's perceptions are accurate to minimise unnecessary anxiety.<sup>31</sup>

Research has also explored the relation between communication and symptoms of post-traumatic stress disorder. Within families where one parent had cancer, greater problems in communication (with either an ill or a healthy parent) were associated with greater symptoms of post-traumatic stress in 212 adolescents (11–18 years) in the Netherlands.<sup>32</sup> Issues such as an absence of sharing feelings or avoiding talking about particular topics with either their ill or healthy parent, were significantly related to higher scores on the avoidance subscale and total distress on the Impact of Events Scale, for both sons and daughters. Sons also reported more intrusive and distressing thoughts when communication was problematic.<sup>32</sup> Open communication (ie, quality of exchanging information, freedom in communication, comprehension, and satisfaction with communication) between daughters and their healthy parents was associated with fewer symptoms of intrusion, avoidance, and total distress.<sup>32</sup>

Although there are many studies supporting the value of talking with children about a parent's life-threatening condition, this value is not universal. A quantitative study in the UK with 80 children and adolescents (8–16 years) who had a parent with cancer found no association between measures of child adjustment (ie, child-rated anxiety and maternal ratings of child behaviour) and communication.<sup>33</sup> Similarly, a quantitative study in Greece of 101 parents and 56 children (4–17 years) in which one parent was affected by multiple sclerosis found no association between communication around illness and family functioning.<sup>34</sup> However, a South African study found that mothers' disclosure of HIV diagnosis to their adolescents (11–16 years) was associated with an increase in behavioural, but not emotional, problems.<sup>35</sup> Nonetheless, the strongest predictors of behavioural problems were family factors, with fewer symptoms reported in children with better parent-child and inter-parental relationships.<sup>35</sup>

The relation between psychological wellbeing and communication might be more nuanced over time. An observational study of the effect of HIV disclosure on 395 adolescents (11–18 years) in the USA found that problem behaviours (ie, unprotected sex, alcohol use, drug use, and contact with the criminal justice system) were higher in adolescents who knew their parents' HIV status at the time of recruitment to the study than those who did not know.<sup>36</sup> However, there were significant differences in the trajectory over the following 5 years with problem behaviours decreasing over time among

the children who knew and increasing amongst those who did not.<sup>36</sup>

Research has examined the relation between the amount of information given to children and psychological outcomes. The previously mentioned Greek study<sup>34</sup> (n=56; 4–17 years) found that children who had partial information about parental multiple sclerosis (eg, they were aware of a parental health problem, but had scarce, unspecific, or developmentally inadequate information) had more social and emotional difficulties compared with children who had been given either no information or total disclosure about their parent's condition. In a cross-sectional study in South Africa of 395 mothers who were HIV-positive with children aged 6–10 years, only 29 of 395 children had been informed of their mother's HIV status and 18 children had received partial disclosure (told that their mother was sick).<sup>37</sup> This partial disclosure group had fewer internalising and externalising behaviours and improved skills of daily living, compared with those who had been told nothing.<sup>37</sup> However, there was no such association for those explicitly told about HIV compared with the non-disclosure group. The differences between these two studies might reflect the specific complexity of HIV disclosure, although the small sample sizes limit the interpretation.

#### Evidence from intervention studies

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

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

from pre-bereavement to 6 months after death, greater decreases in child (7–17 years) anxiety and depression scores were reported for the intervention group.

An RCT in the USA with 307 parents diagnosed with HIV or AIDS and their adolescents (n=412; 11–18 years) compared an intervention to improve behavioural and mental health outcomes of adolescents and their parents with standard care.<sup>42</sup> The initial eight parent-only sessions focused on coping with illness and disclosure. The 16 subsequent parent and adolescent sessions included: parental awareness of children's needs, making custody arrangements, and resolving conflicts. Adolescent topics included disclosure of a parent with HIV or AIDS, dealing with stigma, and encouraging safer sex. The intervention group had better adolescent outcomes (adolescent-report): lower levels of emotional distress and family-related stressors, fewer behavioural problems, and higher levels of self-esteem than did the control group at 24 months follow-up. Parents in the intervention group had lower levels of emotional distress and fewer problem behaviours than did the control group.<sup>42</sup> For both groups, levels of disclosure were high; at study entry 71% had disclosed to at least one adolescent within the family, and at the 2-year follow-up, disclosure had increased to over 85% of all adolescents in the family.

Interventions to facilitate communication about parental life-threatening conditions (specifically HIV) have been evaluated in LMICs. In a rural South African population with high levels of HIV, an RCT tested whether an intervention (Amagugu), consisting of six home-based counselling sessions delivered by lay counsellors, increased HIV disclosure by mothers who were HIV-positive to their children (n=464; 6–10 years) who were HIV-negative.<sup>43</sup> The intervention included a session for the mother to help her to emotionally process the effect of the diagnosis on herself, and to anticipate children's common reactions and questions following disclosure. During the sessions, the mother and counsellor identified other people with whom the child could discuss HIV. Materials provided to the mother included a Body Map to explain HIV in an age appropriate, non-stigmatising manner. The control group received an enhanced standard of care which included one clinic-based counselling session to promote disclosure. The intervention group was found to have higher rates of maternal HIV disclosure, and improvements in health-care engagement, care-planning for the child, and the mother-child relationship than did the control group. There were no differences between the groups for maternal and child mental health outcomes. However, subsequent analysis showed that where disclosure was undertaken, irrespective of group, it was associated with improvements in maternal and child mental health.<sup>43</sup>

A pilot RCT in Rwanda (82 families; 170 children aged 7–17 years) compared a family strengthening intervention with treatment as usual.<sup>44</sup> The family strengthening

intervention aimed to improve family communication and child mental health, and promote disclosure of parental HIV to children. The intervention consisted of an introductory session and six home-based modules addressing psychoeducation about HIV, communication skills, problem solving, and developing a social support network. Parents and children had separate meetings involving psychoeducation and role plays to prepare for a family session to develop a narrative of the family's strengths. At follow-up, there were reductions in children's depression scores compared with treatment as usual, but there were no differences in conduct problems or parenting scores.<sup>44</sup> Parenting and family unity initially decreased but "resolved over time".<sup>44</sup> The authors suggested that this might reflect an initial loss of trust and associated challenges in the family relationship, which is then mitigated by the family-based intervention.<sup>45</sup>

### Effect of communication on parents and the wider family system

Studies have found that sharing information can encourage trust between children and parents. A UK qualitative study of 32 mothers with breast cancer found that some decided to share the diagnosis with their children (n=56; 5–18 years) to maintain trust and facilitate discussion within the family.<sup>46</sup> A qualitative study in Zimbabwe of 41 adults and 56 orphans (aged 7–22 years) found that secrecy can leave adolescents with feelings of resentment, broken trust, and anger.<sup>11</sup> Bereaved adolescents

felt that telling the truth "is the best thing" and that they had experienced "hatred" towards the surviving members of the family who had withheld information about their parent's illness.<sup>11</sup>

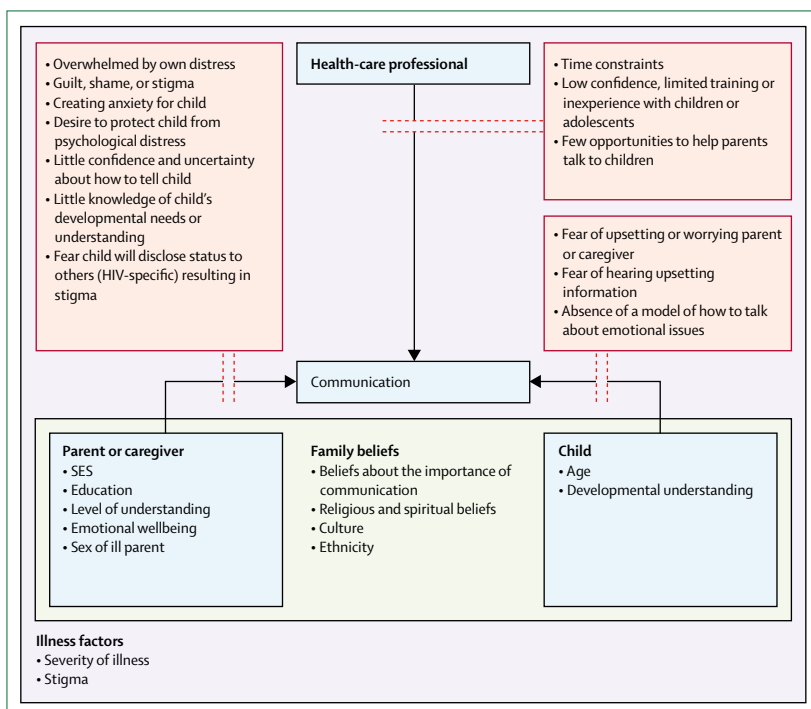
Some studies indicate potential psychological and physical health benefits for parents following interventions to enhance communication with their children around illness. Evaluation of the uncontrolled Danish study<sup>40</sup> previously mentioned found an increase in family functioning and a significant decrease in depression for mothers after the intervention.<sup>40</sup> An uncontrolled intervention study in South Africa (281 mothers and 281 children) designed to facilitate maternal disclosure to children who are HIV-negative (6–10 years), found significant improvements in maternal mental health and emotional functioning, although these benefits occurred irrespective of whether the mothers disclosed to their children during the course of the study.<sup>47</sup>

There might also be physical health benefits of communication; 135 mothers with HIV in the USA who had not disclosed their status reported sometimes skipping medications because they were afraid that their children (6–11 years) would observe them and then suspect something was wrong.<sup>27</sup> These mothers were also more likely to miss medical appointments than those who had disclosed their HIV status.

### Factors that influence the process of communication

Studies have explored factors that might influence communication with children about their parent's condition, including the child's age and sex, family sociodemographic factors, parental health, and illness beliefs (figure). Evidence from studies examining HIV disclosure found that parents are more likely to disclose their status to older children.<sup>10,36,48</sup> Focus groups with 60 mothers who were HIV-positive in India reported that 38% of women suggested it was best to wait until their children (0–10 years) were older (some reporting this to be at least 15 years old) and able to understand the effect of HIV on the family.<sup>49</sup> A UK study found that the child's age predicted when communication about breast cancer occurred between 32 mothers and their children (n=56; 5–18 years), with older children (12 years and over) more likely to be told earlier and given information.<sup>50</sup> These studies also suggest that parents might underestimate younger children's awareness of parental illness<sup>13,14</sup> and understanding of illness and death.<sup>18</sup> Parental life-threatening conditions might pose specific challenges for adolescents; their more advanced cognitive skills than children might lead them to understand more, and appreciate the potential gravity of their parent's situation compared with younger children.<sup>51</sup> Illness might also complicate the attainment of adolescent developmental tasks of separation and individuation.<sup>18</sup>

Some studies have found no relation between rates of HIV disclosure and ethnicity, marital status, religion,



**Figure:** Factors influencing communication with children and adolescents who have a parent with a life-threatening condition

Double red lines represent barriers to communication. SES=socioeconomic status.

employment status, socioeconomic status, race, mother's age, and educational level.<sup>36,48,52</sup> However, disclosure was related to income in a group of 87 African-American mothers (children aged 6–11 years) where disclosure was more likely in families with lower incomes compared with those with higher incomes.<sup>48</sup> In addition, a South African study found that mothers (n=281; children aged 6–10 years) with a current partner were more likely to fully disclose their HIV status than those who were not in a partnership,<sup>53</sup> but this finding was not replicated in a US study (n=88; children 5–18 years).<sup>52</sup> Mothers were also more likely to disclose their HIV status to their daughters rather than to their sons,<sup>36,48</sup> and mothers were more likely to disclose their status earlier than were fathers.<sup>36</sup>

The decision to communicate a parental life-threatening condition appeared to be influenced by the severity of the illness, with disclosure more common among parents who were in poorer health.<sup>36,54</sup> A quantitative study of 281 mothers who were HIV-positive (children aged 6–10 years) in South Africa, found those who considered their health diagnosis as excellent (compared with those who did not) were less likely to disclose their diagnosis.<sup>53</sup> Disclosure of HIV can also be related to the severity of physical symptoms, with a higher proportion of disclosure in families where mothers (n=87; 6–11 years) reported being more bothered by physical symptoms.<sup>48</sup> A parent (n=21) becoming very sick was reported as a compelling reason for disclosure to their children (n=24; 5–18 years) in a qualitative study in Botswana.<sup>10</sup>

By contrast, a Dutch quantitative study (n=212; 11–18 years) found that communication was more open for daughters, when parents were undergoing non-intensive (surgical only) treatment for cancer, compared with those on intensive treatment regimens.<sup>32</sup> Communication was less problematic for sons when parents were undergoing non-intensive cancer treatment, compared with those on intensive regimens.<sup>32</sup> Daughters also rated communication with the ill parent as significantly more open than that with the unaffected parent, although this could relate to the sex of the ill parent (predominantly mothers in this study).<sup>32</sup>

Parents expressed varied motivations for disclosing their HIV status including avoiding unexpected shock if the parent dies; making sure the family knew the real cause of their illness (and death); and protecting children from stigma and feelings of hurt if their child learnt the cause from someone else.<sup>55</sup> Some parents hoped that disclosing their HIV status to their children would alert them to the risks of becoming infected with HIV through unprotected sex or drug use.<sup>55,56</sup>

Studies have noted the consequences and difficulties that parents have experienced by not disclosing their HIV status; parents were concerned they would accidentally disclose their status in a moment of stress or high emotion.<sup>54,57</sup> These situations deny the parent time to prepare, or make the communication process as supportive as possible. In addition, by keeping their HIV

status secret the implicit message communicated is that HIV is stigmatising and must be hidden.<sup>36</sup>

### Barriers and challenges to communication

Children's difficulties in communicating about life-threatening conditions mirror themes expressed by parents, with children reporting that communication is often impeded by fears of upsetting their parents and a desire to protect their parents by avoiding talking about illness (figure).<sup>17,25</sup> Children (n=7; 11–15 years) reported finding it difficult to initiate conversations with parents.<sup>58</sup> Difficulties might be related to a sense of guilt and selfishness about burdening parents with their own feelings.<sup>59</sup> Children's avoidance of talking with their parents can, in part, be due to not wanting to hear upsetting information.<sup>58</sup> Similarly, the fear of losing a parent can lead to barriers; in one study, sons reported more problems in communicating with parents who had a recurrence of their illness compared with sons whose parent's illness was not recurrent.<sup>32</sup> Children might be aware something is wrong, but feel that they do not want to know what it is. A qualitative study in the USA of 87 children aged 7–11 years found that some children experienced a "frightening anticipation" and simultaneous need for denial of their parent's possible death, and thus would not communicate with their family.<sup>19</sup> Teachers' ratings of child behavioural difficulties were higher than those by parental report, suggesting that children (n=80; 8–16 years) are more likely to manifest their emotional distress at school rather than home.<sup>33</sup>

Parents often do not know how to tell their children about their illness<sup>10,25</sup> and want support, ideally from a health-care professional.<sup>60</sup> Studies indicate that parents do not talk to their child about their illness because they believe that their child is too young or unable to understand.<sup>46,55</sup> Parents report feeling unsure about how much information is appropriate,<sup>61</sup> at what age they should talk to their child,<sup>55</sup> or how information should be tailored to their child's age and developmental ability.<sup>25,46</sup> Parents (n=18; 23 children under 18 years) might not be confident in how to respond to children's reactions or questions,<sup>60</sup> particularly about death,<sup>46</sup> and find it difficult to be honest when the illness has an uncertain course or prognosis.<sup>62</sup>

Parents often fear being overwhelmed by their own distress,<sup>61</sup> guilt about not being able to fulfil their role as parents, and grief about missing their child growing up into adulthood.<sup>25</sup> Parents worry about how to manage the reactions of their children in response to the information given and, as a result, might rely on technical or factual language in an attempt to minimise the child's emotional reactions.<sup>61</sup> Studies both in HICs and LMICs highlight parents' fear of causing their child distress,<sup>10,15,35,55,63</sup> or creating anxiety<sup>10,46</sup> or an unnecessary psychological burden.<sup>56,64</sup> Two studies from LMICs also highlighted parental concerns that disclosure of their HIV status would have a negative effect on their child's academic performance at school.<sup>49,64</sup>

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

**Children's preferences about how information is communicated**

*Information*

- Children consistently report wanting prompt, clear, and simple information about their parent's diagnosis, planned treatment, and prognosis<sup>23,72,73</sup>
- The risk of creating anxiety is outweighed by children's desire for information<sup>17,74</sup>
- Children want more information when their parent becomes sicker<sup>23</sup>
- Some children want parents to filter, or soften, the information according to what they feel able to deal with; this desire can create tension between a conflicting desire for complete honesty and reassurance that everything will be alright<sup>25</sup>
- Given paced information so there is time to process content and avoid feeling bombarded or overwhelmed<sup>73,59</sup>
- Given specific information about parent's care needs so they can help and be useful<sup>17,25</sup>
- Information about side-effects and changes associated with the illness or treatment (such as grumpiness, appearance postoperatively, or hair loss following chemotherapy) enables children to prepare themselves and reduces feelings of anxiety,<sup>22,23</sup> and ensures that children do not misinterpret normal treatment side-effects as deterioration in their parents' health<sup>59</sup>
- Information about range and intensity of emotions experienced by other adolescents in same situation<sup>23</sup>

*Sources of information*

- Direct and honest information from parents as early as possible<sup>74</sup>
- Information from parent's clinician
  - Information from a knowledgeable source<sup>22,23</sup>
  - Ability to obtain information without fear of upsetting parent<sup>61</sup>
  - Visit to clinic can dispel scary fantasies about treatment and humanise the doctor;<sup>59</sup> phone number is helpful even if never used<sup>23</sup>
  - Need health-care professionals to be proactive as it is hard to approach them directly<sup>25</sup>
  - Children want their own relationship with the health-care professional to be maintained<sup>75</sup>

*Language*

- Avoid jargon to reduce confusion
- Self-referential language should also be used with caution; "they will cut me open" might be more distressing to hear than an objective description with language that disconnects it from the parent<sup>59</sup> (eg, the doctor is going to do an operation to remove the tumour)

*Opportunities for emotion focused communication*

- Children want opportunities to talk and express their feelings.
- Peer support; children often feel isolated from their peer group who have little understanding or knowledge of the challenges facing their family<sup>14,74,76</sup> and want to meet others living through similar experiences in person or online<sup>76</sup>
- Use online chat rooms to exchange feelings and experiences (rather than information);<sup>51</sup> might reflect developmental preferences of adolescents, or fear of burdening parents, or feelings of guilt or selfishness about talking about own feelings at home when parent is unwell<sup>59</sup>
- Helpful if parents invite adolescents to talk (potentially offering several times); adolescents feel this indicates parents want to hear about their perspective<sup>59</sup>
- Unobtrusive support exemplified through allowing space<sup>74</sup>

*Opportunities to ask questions*

- Discuss worries about causes and heritability of illness; economic effect of illness on family<sup>22,23,58,73</sup>
- Option to talk about the possibility of their parent's death<sup>23,72,73</sup> and who will care for them after their parent dies<sup>73</sup>

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

*Parents describe feeling*

- Overwhelmed and frightened about sharing diagnosis while managing own emotional reaction<sup>61</sup>
- Anxious about harming children through not telling them in right way or at right time<sup>55,77</sup>
- Unable to answer potential questions about the source of the illness<sup>78</sup> and concerns about the child maintaining confidentiality of the diagnosis<sup>79</sup>

*Parents describe wanting*

- Shared responsibility with health-care professional for child's wellbeing<sup>77</sup>; parents report rapport with health-care professional facilitated disclosure<sup>79</sup>
- Time with clinician to discuss what to say<sup>22,46,55</sup> and what language to use<sup>57</sup>
- Guidance about children's understanding of death, appropriate language to use<sup>46</sup> including appropriate leaflets or books with pictures to share<sup>22,70,75,79</sup>
- Information about how other families coped, children's normal reactions to understand their behaviour<sup>22</sup>
- Flexibility about timing of disclosure conversation<sup>79</sup>

Parents with HIV reported specific challenges linked to the sense of shame and stigma sometimes associated with HIV.<sup>10,63</sup> Parents worried that their child would experience discrimination and stigmatisation from

others. They feared that children would not keep information about their diagnosis confidential,<sup>10,12,49,55</sup> and that disclosure would increase the vulnerability to stigma of the family.<sup>27</sup> Parents expressed their concern about

the potential response of their children to the news of their HIV status, fearing rejection,<sup>56</sup> a loss of respect from their child,<sup>55</sup> discrimination,<sup>49</sup> or a refusal to care for them.<sup>64</sup> Potential embarrassment at coping with questions about how the disease was contracted and fear that this might raise broader questions about sexual relationships (which is taboo in some cultures) also contributed to parents' reluctance to talk to their children.<sup>55,56</sup> The relation between stigma and parental disclosure is inconsistent; parents who perceived their children to be experiencing higher HIV-related stigma were more likely to disclose their condition<sup>56</sup> whereas another study found no such association.<sup>65</sup>

A German study of participants recruited from cancer registries found that although 1194 (66%) of 1809 cancer survivors with children (under 22 years) wanted support about how to tell children about cancer, only 161 (9%) accessed family centred support.<sup>66</sup> A systematic review of interventions for families with parental cancer identified barriers and facilitators for engagement with psychosocial support services.<sup>67</sup> This review highlighted the parents' perceived importance of interventions that were appropriately structured and targeted, in addition to

consideration of practicalities, such as child care that would enable parents to access interventions. Evaluation of a support group for 21 parents with recurrent cancer noted that parents had not anticipated positive gains for themselves from attendance, but overcame their reservations if they felt it might benefit their children (n=30; 4–8 years).<sup>68</sup> Despite these hesitations, parents reported finding the group a valuable experience, underlining the importance of engaging parents when planning interventions.

Parent-reported communication might differ from child-reported experiences.<sup>22</sup> Parents might try to conceal and control their own distress to protect their children, but in a study of 26 fathers and 31 children aged 6–18 years who had a mother with breast cancer, children were often acutely aware of their father's emotional state and, in turn, concealed their own distress to protect their father.<sup>22</sup> Fathers reported that they had fully reassured their children about their mother's health, yet children still reported feeling worried.

The extent to which parents are able to accurately assess their child's understanding, and consequently tailor communication, has been questioned.<sup>17</sup> When a parent is

	Detail	Challenges	Suggested phrases for parent	Suggested phrases for children
Prepare yourself	Examine your own comfort levels and beliefs. Ensure parents can see a calm and focused person who is emotionally available. Use of supervision or consultation and peer support can be invaluable. Consult relevant disease specific guidelines if available. <sup>80,81</sup>	Time pressures and work load	..	..
Prepare information	Try and establish if patient has children. Consider what ongoing input you can offer parents and children (eg, availability for direct contact with children). Check that you know the names of the parents and names and ages of children to ensure language and content is developmentally appropriate. Addressing family members by name will make the consultation more personal. Consider how to initiate the conversation about patient's children.	Might be difficult to establish if adult patient has children (eg, in the Accident and Emergency department). Adult clinicians might feel unskilled or inexperienced talking about children.	"Can you tell me about your family?" "Who lives at home with you?"	..
Prepare environment	Consider suitable location (quiet or private) and timing of conversation with parents (both if possible) and children.	Private or quiet space might not be available.	"Let's move to this quieter space so that we can spend some time talking together."	..
Explore parents' views about talking to their children	Acknowledge concerns that parents might have about telling their children. If parents express doubt about talking to their children explain that they might have already noticed changes—eg, physical and emotional changes, and absences—which lead to children's distress. Suggest it is better to talk to children so they are not alone with their worries, or find out the diagnosis from another source, especially if ongoing treatment and changes in physical state. It might be helpful to discuss their children's developmental understanding of illness. <sup>18</sup> Acknowledge emotional aspects of a parent telling their child about their condition and desire to limit child's distress. Explore parental fears or barriers to talking to their children. Problem solve around perceived barriers, while respecting parent's role, wishes, and beliefs.	Parents might feel reluctant to talk to their children; reassure parents that it is not uncommon to feel this way. It can be helpful to tell parents there is no hurry to decide, that they can give this decision some thought, and another meeting can be arranged in a few days.	"Thinking about talking to your children about this probably feels like the hardest thing in the world. It's completely understandable to want to protect them from this news. Are there particular things that make this even harder for you?" "I wonder if your children have noticed that you've been losing weight or have been unexpectedly away from home a lot recently?" "We know from experience that sometimes when we don't share things about illness with children, they often realise something important is happening. They have active imaginations and what they imagine can even be worse than the reality." "We know that you know your child inside and out. We appreciate you are the expert in your child and we will always work with you."	..

(Table continues on next page)



Detail	Challenges	Suggested phrases for parent	Suggested phrases for children
(Continued from previous page)			
<p>Prepare the parents</p> <p>Acknowledge and support parent with their own feelings and distress about their diagnosis. Prioritise key information for parents—they might struggle to assimilate information because of fatigue, pain, or emotional distress. Discuss with parent timing of information about life-threatening condition. Encourage parent to ask the child how much they know about the life-threatening condition and pace subsequent information in response to children’s emotional reactions and wishes; the conversation might need to take place on several different occasions. Discuss with parent how best to describe the life-threatening condition; suggest simple phrases or narratives the parent could use to explain the life-threatening condition to their children, including the name of their life-threatening condition, what they might observe, and what they should expect. Encourage parent to only convey information that is true and can be elaborated in due course; this is important to maintain the children’s trust in their parent or caregiver. Suggest to parents they might find it helpful to prepare a script and practice this before talking to their children. Suggest parent might find it helpful to include their partner, a family member, or friend in their conversation with the children. Highlight to parent themes from literature about what children report is important in communication about life-threatening conditions. Offer parent resources (eg, leaflets, story books, or web resources) to share with their children. Encourage parent to check children’s understanding of what has been communicated and importance of repeating key messages.</p>	<p>If parents are separated, discuss with parents who will tell the children and the involvement of the other biological parent.</p>	<p>“Would you like to sit and talk with me now about how you will tell your children and what words you could use? If you like, we can then practice this together.”                      “I know you are worried that telling your children will be upsetting for them. Yes, it is likely they will be upset or even angry. These are natural emotions and responses to have. Be assured that talking to children is important in helping them through this difficult time.”                      “Younger children might focus much more on the practical aspects of how the life-threatening condition will change their day to day life; who will take me to school? They might not show an immediate reaction to the news (for example wanting to go and play) but this doesn’t necessarily mean they didn’t hear the news and distress can be shown in other ways.”</p>	<p>“Today we went to the clinic because Dad hasn’t been feeling well. Shall I tell you a bit more about what the doctors told us?”                      “You know that Mummy hasn’t been feeling well and we needed to find out what was wrong. We went to the hospital where the doctors did some special tests to try and find the problem. Today the doctors told us Mummy is ill because she has an illness in her blood called cancer.”                      “The doctors are giving Dad some strong medicine called chemotherapy to try and treat the cancer. We hope this will help him get better, but it will also make him feel very tired.”                      “The doctors and nurses are trying very hard to make Mummy better and I really want Mummy’s medicines to work but sometimes medicines do not work.”</p>
<p>Reassurance for parents that discussion will not cause more problems</p> <p>Reassure parent it will not cause harm to share some of their emotion with children but that openness does not mean sharing full expression of their own grief. Encourage parent to consider how they can or want to model for their children in responding to the life-threatening condition (eg, sharing emotions, possibly using humour).<sup>82</sup> Labelling emotions (eg, sad, scared, or angry) is useful and allows modelling of emotional sharing and expression. Help parent feel confident to reassure their child that they will be loved and looked after no matter what the future holds.</p>	<p>Alert parent to children’s common reactions—eg, sadness, anger, and reassure parent that these are normal responses and does not mean the parent has done the wrong thing, or that the child does not want further information at a later date.</p>	<p>“It’s ok to talk with your children about how scary and sad this news is. Sharing your feelings can be helpful, but children might find it frightening to see you completely overwhelmed with distress.”                      “It is useful if you name your emotion, for example explain that you are feeling sad and that you are crying because sometimes you feel a bit sad and you feel better after a good cry.”</p>	<p>“I know that this is sad and scary to think about, but it’s better that we share how we are feeling and talk about our worries, rather than having to struggle with it by ourselves.”</p>
<p>Common questions</p> <p>Support parent to nurture children’s confidence to initiate conversation and ask question. Anticipate common questions that children might ask. Parents might benefit from rehearsing with you how to answer these questions at a developmentally appropriate level; this also provides an opportunity for you to check parents’ own understanding of their condition. Encourage parent to reassure their children that their distress is normal and acceptable. Discuss ways parent can encourage children to ask questions as they arise and review their children’s feelings regularly. Discuss with parent the possibility older children might independently seek further information online which might be of varying factual quality Encourage parental dialogue with their children about online information.</p>	<p>Questions about the possibility of parental death are disease and stage specific. Answers need to consider child’s age and level of understanding.</p>	<p>“Children often want to know what caused the illness and are worried that it might have been their fault.”                      “Your children might ask you if you are going to die, who will look after them and whether they can catch it. Shall we plan how you might deal with these questions at home?”                      “Would it be helpful to have a session with you and your children together?”</p>	<p>“Would you like to talk to the doctors; you can come with me one of my clinic visits?”</p>

(Table continues on next page)

Detail	Challenges	Suggested phrases for parent	Suggested phrases for children
(Continued from previous page)			
Future thinking	Discuss with parent how they can involve children in day-to-day aspects of the life-threatening condition. Encourage parent to establish a new normal while maintaining boundaries and hobbies where feasible. Encourage the parent to share the practical and emotional burden with the well parent, family, and friends. If parents are separated, discuss the benefits of maintaining a consistent message for their children. Identify who else knows about the life-threatening condition and who the child can talk to. Explore the importance of children's teachers and school. Identify ongoing sources of support and community resources (eg, parent groups, voluntary sector, online forums or websites, written story books and other online resources <sup>63</sup> ). Discussion might need to include consideration of who will care for the children if the parent is hospitalised, or for single parents, custody arrangements.	<p>"If you can, do accept offers of practical help or emotional support from friends and family with whom your children feel comfortable, to keep their day to day routine."</p> <p>"Children spend a large amount of time at school and so it is important for the school to understand what your child is going through. School can also be a really helpful source of support for your child. Try to keep the school up to date."</p> <p>"It will be really helpful for your children to have somebody to talk to outside of the family. Being able to share their feelings without worrying about upsetting you is really important."</p>	"I know it can feel scary when you don't feel sure about what's going to happen. I feel that way sometimes too. What I do know for sure is that I love you very much. We will work through this together as a family, whatever the future holds."

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

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

Although parents often adopted a model of communicating facts rather than emotions, parents wanted their children to share more of their feelings.<sup>17</sup> Children reported that their parents were similarly uncommunicative about their own emotions. Parental focus on practical aspects of illness might reflect parental fear about how to manage powerful and upsetting emotional conversations, and how to adequately contain and manage their child's reaction.<sup>17</sup> Parents' concern about revealing the extent of their own distress can create difficulties in communication about emotional issues between parents and children. Children are often aware of how their parents are feeling, but strive to protect them by concealing their own distress.<sup>22,61</sup> Parents might also interpret their child's response in the context of their own preferred coping style; parents who preferred not to talk about their illness perceived their child was coping well when they did not ask questions.<sup>61</sup> Conversely, parents with an open communication style viewed children's questions as a sign of successful coping.

Health-care professionals working in adult-focused services might feel inexperienced about talking to children and adolescents about parental illness. They might feel unprepared to facilitate the care that patients want and expect in supporting their family throughout the illness and in bereavement.<sup>61</sup> In some LMICs, clinics

might be a long distance from the family home, providing few opportunities for the health-care professional to help the parent to talk to their children.<sup>69</sup> Often, the health-care professional responsible will have received no, or limited training in helping with communicating about illness (n=35).<sup>70</sup> There are also cultural differences in preparing for death; in some communities around the world talking about death or dying is considered taboo.<sup>71</sup>

### Reported preferences about how diagnosis and information is conveyed

The research literature presents themes that are important to children, adolescents, and their parents in the content and delivery of communication (panel). It is important to acknowledge that most child participants were adolescents with cancer from HICs, but their views offer invaluable and practical guidance for health-care professionals applicable across multiple health-care settings. The preferences should be viewed in the context of children's developmental understanding of illness and death.<sup>18</sup>

### Expert group workshop and development of framework

The expert group of clinicians and researchers with extensive experience of working with families affected by life-threatening conditions in HICs and LMICs met for a two-day workshop in Oxford, UK, in 2017.<sup>18</sup>

In developing these guidelines (table), we appreciate that a range of health-care professionals will be involved in these discussions; in HICs these will more likely be oncologists, family practitioners, or infectious disease specialists, whereas in LMICs, these will be medical officers, nurses, or community health-care workers. Different cultures and what is appropriate to discuss with children must be considered, while upholding the

principles of the UN Convention on the Rights of the Child.<sup>84</sup>

### Limitations and future directions for research

The literature is complicated by methodological difficulties; participants have been recruited from a range of sources, most frequently through the parent's hospital oncology or HIV services, but also from charities and voluntary organisations, community adverts,<sup>16</sup> or population-based surveys.<sup>15</sup> Most research has also focused on mothers rather than fathers. Comparisons of studies can be compromised by differences in the stage of parental illness at the time of data collection ranging from newly diagnosed<sup>22</sup> to 10 years since bereavement.<sup>15</sup> Some studies restricted participants to a relatively discrete time frame (eg, 2–5 months since diagnosis),<sup>14</sup> whereas others were much more wide-ranging.<sup>32,34</sup> These factors might contribute to a loss of detail and specific needs at particular stages of the disease, or conversely the value of reflection on the whole illness journey, and how communication needs might change over time.

The influence of the socioeconomic and geographical context on treatment availability and prognosis also affects generalisability. Work in LMICs is almost exclusively limited to parents with HIV (rather than with other conditions) and the specific stigma associated with HIV might affect the relevance of findings from this group for other life-threatening conditions. Only three studies<sup>11,24,37</sup> done in LMICs directly involved children as research participants (in contrast to HICs); future research must strive to sensitively include children as active participants. Most studies recruited children over the age of 11 years, which might limit the applicability of research to younger children, although children as young as 6 years have been interviewed.<sup>14</sup> The relatively wide spread of ages within individual studies<sup>14</sup> risks overlooking the specific needs of different age groups and developmental transition points.

The fear of the emotional effect of diagnostic conversations on health-care professionals, parents, and children is the predominant, underlying reason for these not occurring. Similar concerns might also extend to and inhibit the research agenda. Identifying what support is required is needed to overcome these emotional barriers and how this could be sustainably delivered, particularly in contexts where the disease burden is high and resources are limited. A programme of formal communication skills training is crucial, both in medical schools and other health-care curricula, and part of continuing professional development for front-line health-care professionals. Evaluation of training and how this translates into enhanced clinical practice is essential.<sup>7</sup>

Models of family-centred care (in paediatrics) which acknowledge the effect of a child's illness on all members of the family, have been adopted in many HICs.<sup>85</sup> Given the effect of parental illness on child outcomes, it is timely to consider how a similar model could be of benefit in the management of adult patients and their

families. As a minimum, services should provide proactive support and guidance for parents about communicating diagnoses to children. Adult clinicians should take overall responsibility for ensuring parents have support, and should discuss with parents whether they would like an appropriately trained health-care professional to facilitate this support directly through a family consultation.

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

#### Contributors

AS conceptualised and designed the review. LD, LH, and AS undertook the literature searches and selected the studies. AS, LD, and ER gathered the information from the studies and drafted the manuscript. SZ, TR, AY, BK, and RB contributed to writing specific 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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