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Exploring the experiences of healthcare professionals in South Africa and Uganda around communicating with children about life-threatening conditions: a workshop-based qualitative study to inform the adaptation of communication frameworks for use in these settings

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ABSTRACT

Objectives This study aimed to explore how published communication frameworks could be amended to ensure applicability and cultural appropriateness for professionals to support family-centred conversations by investigating' healthcare professionals' (1) experiences of providing support to families when a caregiver or a dependent child (<18 years old) has a life-threatening condition, (2) perceived challenges for caregivers and healthcare professionals in communicating with children about illness, (3) perceptions of how clinicians could be equipped to facilitate conversations between caregivers and children about an adult or the child's own life-threatening condition and (4) suggestions for amendments to previously published guidelines to ensure cultural relevance in South Africa and Uganda.

Design A qualitative study involving two 2-day workshops with embedded focus group discussions, break out rooms and consensus discussions.

Setting Health and social care and third sector organisations in South Africa and Uganda.

Participants Thirty-two professionals providing care to families affected by life-threatening conditions in South Africa or Uganda who were aged 18 years or older and able to converse in English.

Results Participants identified obstacles to having conversations with caregivers about children and to telling children about serious illness during consultations. These included patients' beliefs about illness, medicine and death, language barriers between families and the healthcare team, and emotional and practical challenges for professionals in having these conversations. Culturally appropriate adaptations were made to previously published communication frameworks for professionals to support family-centred conversations.

Conclusions Culturally sensitive communication frameworks could help healthcare professionals to talk with families about what children need to know when they or a caregiver have a serious illness. More broadly, effective communication could be facilitated by promoting healthcare professionals' and communities' understanding of the benefits of telling children about illness within the

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Workshops with embedded focus group discussions, break out rooms, consensus discussions and experienced research team field notes provided a rich source of data beyond what might be achieved by a focus group or consensus group alone.
⇒ The frameworks being amended in the study were published, evidence-based and not specific to a particular disease increasing their usability in multiple clinical disciplines.
⇒ Participants worked in a range of clinical settings with different professional roles and included those who could speak one or more African languages allowing for an appreciation of words and concepts that can, and cannot, be translated or understood in other cultures.
⇒ Workshops took place in Uganda and South Africa only, limiting their cultural applicability to other countries in sub-Saharan Africa.

family. Together these strategies may mitigate the psychological impact of global disease on children and their families.

INTRODUCTION

Every day around the globe millions of children and adults receive a diagnosis of a life-threatening condition. For example, in 2020, 37.7 million people globally were living with HIV; sub-Saharan Africa accounted for 64% of these HIV infections.[1] Furthermore, rates of noncommunicable diseases in sub-Saharan Africa are rapidly increasing and it is predicted that this will be the leading cause of mortality in the region by 2030.[2] One of the most challenging tasks for parents and caregivers is to tell children (<18 years old) that either they or a parent/caregiver has a serious illness.[3 4] Parents want to protect children from the potentially distressing news of a diagnosis, or believe children are too young to understand what is happening.[5] Consequently, children may be given limited or no information about their own or a parent's life-threatening condition.[3 4] However, not telling children about a serious illness does not mean that they are unaware; a study of bereaved children and adolescents in Zimbabwe indicated that although very few had been told their parent's diagnosis, many knew or had a strong suspicion that their parent had had HIV.[6] Children are 'astute observers' and attempt to make sense of the situation by themselves; in the absence of accurate information from adults, children may hold specious beliefs about the situation[7] and must cope with the emotional consequences alone.

Reviews of the global evidence regarding communication with children about their own or a parent's life-threatening illness indicate that effective communication is associated with better psychological and family outcomes as well as improved treatment adherence and disease management.[3 4] Children have expressed their wish for both honest information about illness and an opportunity to talk about the emotional impact of the news.[8] Parents frequently look to their healthcare team for advice and support as they prepare to share information with their children about illness[9 10]; a South African study found that 96% of parents or caregivers who had not discussed disclosure of their child's HIV diagnosis with a health professional wanted this support.[11] However, healthcare professionals describe needing guidance on how to support families communicate with children about serious illness.[12]

A number of interventions to facilitate family communication about a caregiver's HIV diagnosis have been developed and evaluated, demonstrating the benefits of disclosure to children.[13] Different health beliefs and cultural narratives about illness may influence how caregivers communicate with their children about their own or a caregiver's serious illness. These include taboo surrounding the topics of death and dying,[14] or fear that the patient or family may be subject to stigma associated with their medical condition.[5 15 16] An awareness and knowledge of cultural differences are necessary in order to effectively deliver care that meets the cultural needs of patients.[17] This is essential to achieve a shared understanding of the diagnosis and collaboratively agree treatment plans between healthcare providers, patients and families.[17]

Family communication can be facilitated through resources and training for healthcare professionals to support them in talking with their patients about how to share a diagnosis with children.[18] Standardised guidelines for healthcare professionals could help support successful illness-disclosure in families.[19] Healthcare professionals have reported a desire for guidelines[5] and practical instructions to guide their communication for sharing a diagnosis of cancer with patients in South Africa.[20] Specific strategies for communicating the diagnosis of osteosarcoma to Zulu patients[20] and a practice-based framework for paediatric HIV disclosure in Kenya have been published.[19] However, in some low-resource settings such as in areas of Uganda, standardised and culturally appropriate communication guidelines are limited[21] and are specific to certain diseases, for example, HIV.

The current study aims to explore how published communication frameworks[3 4] could be amended to ensure applicability and cultural appropriateness for professionals in South Africa and Uganda to support family-centred conversations with caregivers telling their children (< 18 years old) about a parent/caregiver's or child's life-threatening condition; these frameworks are intended to be generic and thus facilitate conversations about any form of serious illness. The objectives of this study are to investigate professionals':

1. experiences of providing psychosocial care and emotional support to families when a caregiver or a dependent child (<18 years old) has a life-threatening condition in South Africa and Uganda,
2. perceived challenges for caregivers around communicating with children (<18 years old) about their own or a caregiver's life-threatening condition in South Africa and Uganda,
3. perceptions of challenges for professionals towards the provision of family-centred conversations in clinical practice in South Africa and Uganda,
4. perceptions of how clinicians could be equipped to facilitate ongoing conversations between caregivers and children about the child's own or a caregiver's life-threatening condition,
5. suggestions for amendments to previously published guidelines[3 4] to ensure cultural relevance.

METHODS

Workshops with embedded focus group discussions were conducted. A qualitative design was considered most appropriate as the study was concerned with identifying if and how communication frameworks developed and published in the UK could be culturally adapted and made appropriate for clinical use in sub-Saharan

healthcare settings such as South Africa and Uganda. The study is reported in accordance with the Consolidated Criteria for Reporting Research checklist for qualitative research.[22]

Context

The research team are a group of clinicians and researchers with extensive experience of working with families affected by life-threatening conditions in high-income and low-income and middle-income countries. Three members of the research team (LJD, SZ, AS) convened a workshop held in Oxford, UK, in 2017 of clinicians and researchers with extensive expertise and experience of working with children and families affected by life-threatening conditions in LMICs. Informed by the literature, published recommendations and members' academic and clinical perspectives, this iterative process resulted in published frameworks of principles to guide healthcare professionals' communication when a parent or child has a life-threatening condition.[3 4] The workshop discussions described in this paper were held to inform the adaptation of these published frameworks for use in South Africa and Uganda. Healthcare professionals who treat sick children have direct and regular contact with the child through clinics and hospital attendance. Conversely, when a parent is ill, healthcare professionals primarily focus on the adult patient and may never have direct contact with the patient's children. This results in important differences in the frameworks needed for these two professional groups, hence separate frameworks were developed.

Setting

Workshops were conducted in two locations in sub-Saharan Africa: (1) Human Sciences Research Council Durban, South Africa, and (2) Hospice Africa Uganda, Kampala, Uganda in 2019. These sites were chosen due to the research team's longstanding and productive collaborations with health, social care and third sector organisations in these locations.

Study population

Workshop participants were health or social care professionals (hereafter referred to as professionals) providing care to families affected by a life-threatening condition in South Africa or Uganda. This included doctors, nurses and social care professionals. Inclusion criteria also included being aged 18 years or older and able to converse in English in order to participate in the workshops.

Sampling

Using convenience and snowball sampling, a range of professionals were recruited to the workshops. Purposive sampling techniques were used in combination to ensure a representation of professionals from both rural and urban communities and with experience of working with paediatric and adult patients.

Box 1 Outline of the activities and discussions during the 2-day workshop

Day one

Part I

⇒ Introductions—names, institution and role.
⇒ Ground rules—consent for audio recording, confidentiality, respect of other participants' contributions.
⇒ Background to the frameworks.
⇒ Aims and objectives of the workshop.
⇒ Icebreaker.
⇒ Focus group discussion of professionals' experiences of having conversations about the children with families affected by life-threatening conditions.
⇒ Small group activity—perceptions of communication with families affected by life-threatening conditions about the children that went well.
⇒ Small group activity (different groups from previous activity)—perceptions of communication with families affected by life-threatening conditions about the children that went poorly.
⇒ Discussion with professionals about how the frameworks may have influenced the perceived experiences that went well and poorly.

Part II

⇒ Focus group discussion of the frameworks—including relevance, strengths, weaknesses, omissions, additions.

Day 2

⇒ Consensus discussion of how the frameworks could be implemented into clinical practice in their local context including:
⇒ Discussion of the obstacles about the implementation of the frameworks in their local context—review those identified in day 1 and how they might be overcome.
⇒ Discussion of cultural adaptations—across specialty, profession, country, healthcare setting.
⇒ Consensus where possible.
⇒ Reflection on the workshop including what delegates will take back to clinical practice.

Recruitment

Eligible participants were contacted by the International Children's Palliative Care Network (JD) via email and provided with the participant information sheet explaining the purpose of the workshop, why they were invited to take part, and expected involvement. Thirty-two professionals confirmed participation by providing written consent, which was returned to a study researcher (LJD, ER) before the workshop.

Data collection

Two workshops were conducted: 7–8 March 2019 in Durban, South Africa and 6–7 May 2019 in Kampala, Uganda. Participants were provided with the published frameworks[3 4] 2 weeks before the workshop and were encouraged to read and consider their appropriateness for their local context. A range of activities and discussions took place during the two full-day workshops as outlined in box 1. Part I of the workshops explored the broader context of participants' clinical experience of working with children and families affected by life-threatening illness. These discussions provided the necessary foundational understanding and perspective

for the discussions in part II. In part II, each step of the frameworks was presented by the facilitators, who invited suggestions for additions, deletions and adaptations from the participants. All contributions were discussed by the group and deliberated until a consensus was agreed across all participants.

The workshops were facilitated by four coauthors (LJD, ER, AS, JD). SZ was also involved in the facilitation of the workshop in Durban, South Africa. LJD, ER, AS and SZ had no prior relationships with the participants; JD was known to all of the Ugandan participants and many of those from South Africa due to her role as Director of an international Palliative Care charity. The workshops were conducted face to face and were audio recorded for transcription. Facilitators also made field notes about observations throughout the workshops.

Data analysis

Audio recordings were transcribed using intelligent verbatim by the research team. Analyses of part I of the workshops were guided by reflexive thematic analysis which enables researchers to flexibly explore experiences, perspectives and opinions as well as similarities, differences and unexpected insights, and it is not tied to epistemological or theoretical perspective.[23 24] The data were managed using NVivo V.10. LJD, ER and TP manually coded the data detailing inductive descriptive codes by marking similar words or phrases in the transcripts. These codes were then collated and using mind maps identified where some of them merged into themes. A fourth author (JRH) was then consulted to review and refine the themes and preparation of the manuscript. Final themes were discussed, refined and agreed with all authors through critical dialogue.

The data collected during part II (amendments to the frameworks) were collated and circulated via email after each workshop by the authors ER and LJD for feedback. Participants were invited to respond to the suggested changes; all respondents confirmed via email that the changes were a true reflection of the part II workshop discussions and there were no points of conflict that required resolution.

In this study, saturation was considered to have been achieved through agreement across the research team and participants about both the final themes (part I) and changes to the frameworks (part II).

Research team and reflexivity

The research team consists of six female and two male researchers (ER, JRH, TP, SSP, JD, SZ, AS, LJD) all of white ethnicity and at different career and life stages. LJD, JRH, TP, SSP, JD, AS have clinical roles working with patients who have a serious illness (clinical psychologist, nurse, assistant psychologist, doctor, nurse and doctor, respectively). ER is a postdoctoral researcher and SZ is a professor of medical sociology. All members of the research team have experience of academic research on effective communication within healthcare settings; with the exception of two, the research team all have experience of working in low-resource settings, for example, running clinical trials.

The research team were very aware that six members are UK-based clinicians or researchers and four (LJD, ER, SZ, AS) were the authors of the original frameworks[3 4] being amended within this study. Extensive discussions and partnership in planning and convening the workshops with colleagues working in Uganda and South Africa were essential to consider the ways in which the research team's interactions with participants might be influenced by our own professional background, experiences and prior assumptions, or participants' willingness to contribute suggestions and adaptations to the communication frameworks. Collaboration with the Ugandan and South African participants at all stages of the research, from the design and convening of the workshops to completion of the manuscript facilitated consideration of multiple perspectives and a contextual and experiential understanding of the challenges of communication in different healthcare settings.

The workshops were conducted in English as a common shared language but included participants who spoke one or more African languages and consideration of how words and concepts could (not) be translated or understood in different languages, cultures and healthcare settings was a source of rich discussion. These are further explored in subtheme 1.2.

Patient and public involvement

This study was conducted to explore healthcare professionals' views on the adaptations needed to communication frameworks; it did not involve patients or members of the public in the design of the study, conduct, reporting or the interpretation of the results.

RESULTS

A total of 32 professionals (29 female, 3 male) were recruited to the workshops (South Africa n=15, Uganda n=17) from a range of clinical settings and professional roles as summarised in tables 1 and 2.

Table 1 South African workshop participants

Professional role	Clinical setting	Gender	N
Doctor	Hospital	Female	4
Doctor	Hospice	Female	1
Nurse	Charity	Female	3
Nurse	Hospice	Female	2
Social worker	Non-governmental organisation	Female	2
Social worker	Hospice	Female	1
Lay counsellor	Hospice	Female	1
Medical educationalist	Charity	Female	1

Table 2 Ugandan workshop participants

Professional role	Clinical setting	Gender	N
Doctor	Hospital	Female	2
Nurse	Non-governmental organisation	Female	2
Nurse	Hospice	Female	1
Nurse	Hospital	Female	1
Nurse	Not for profit support organisation	Female	1
Nurse	Military	Female	1
Nurse	Community	Male	1
Nurse	Community	Female	1
Social worker	Non-governmental organisation	Female	1
Social worker	Charity	Female	1
Medical clinical officer	Not for profit support organisation	Female	2
Medical clinical officer	Non-governmental organisation	Male	1
Counselling psychologist	Non-governmental organisation	Male	1
Community worker	Non-governmental organisation	Female	1

Overall, two themes were identified from the part I workshop discussions: (1) participants' experiences of conversations with caregivers about children (<18 years old) in clinical practice, with three subthemes: (1.1) beliefs about illness, medicine and death, (1.2) language barriers between families and the healthcare team, (1.3) emotional and practical challenges for professionals to providing family-centred care and (2) participants' obstacles to telling children (<18 years old) about the reality of a life-threatening condition. These part I discussions provided the context for part II of the workshops; the adaptations and rationale for changes applied to the published communication frameworks are presented in tables 3 and 4.

Theme 1: experiences of conversations with caregivers about children in clinical practice

Participants expressed strong personal and professional beliefs about the importance of family-centred communication about illness, reflecting on examples from their clinical work that illustrated their commitment to facilitating and promoting such communication. These are discussed under three subthemes: (1.1) beliefs about illness, medicine and death, (1.2) language barriers between families and the healthcare team, (1.3) emotional and practical challenges for professionals to providing family-centred care.

Sub theme 1.1: beliefs about illness, medicine and death

Professionals often stated they were 'cautious' when using the term 'cancer' to deliver a diagnosis (in a child or adult) in clinical practice as some parents or caregivers (hereafter referred to as caregivers for simplicity and ease of reading), regard this illness as a 'curse' or punishment from a family ancestor in response to a transgression (eg, stealing). For example, a participant described how a child's sarcoma had been attributed to an ancestor 'sitting on their leg' and that the family believed that if the ancestor was 'happy' the sarcoma would 'disappear'.

> "*They want to know what caused the cancer… but it's culturally related. Because in the community [people believe] that somebody has done something for [the patient] to be like this…it doesn't just happen, so somebody must have done something for my child to be like this.*" [Participant 004, South Africa]

Participants were aware of situations where wider community members had been told that a child or adult's diagnosis was for a different illness, such as a heart condition rather than cancer. These decisions were believed to arise from families' concerns that they could be ostracised from the community if people heard of a life-threatening condition, such as cancer or HIV. This was sometimes attributed to beliefs within the community about the risk of disease transmission, and a cultural perspective on disease causation.

> *"Patients sometimes can't get to appointments… they tell me they've not been allowed on the bus, people assume that they are cursed, and fear that it is infectious and others can catch it"* [Participant 012, South Africa]

> "*The culture says if you have a particular sickness you are an outcast, so you're not supposed to relate to the person*" [Participant 016, Uganda]

Professionals did not want to challenge families' beliefs and practices and therefore felt it was inappropriate to initiate a conversation with caregivers about telling children their own or a caregiver's diagnosis. Participants recognised a need to respect the beliefs of patients with regards to the use of traditional (non-medical) methods to treat illness. Professionals felt if the healthcare team acknowledged with families that spiritual and traditional methods could be used to treat the child or caregiver's illness, this could help to promote the clinician–patient relationship and facilitate opportunities for the professional to discuss with caregivers the importance of talking to children about the illness. Participants reflected on their experience that including traditional approaches to treatment facilitated families' acceptance of 'western' medicines and procedures. This was especially effective if traditional methods had been unsuccessful, such as the (child or adult) patient continuing to feel unwell or a tumour still visible.

> *"…the father refused the amputation, although the mother wanted this… they allowed the traditional healing to go ahead first, and the father was grateful they were allowed to do that first…and from then the relationship improved' [Participant 010,* South Africa]

Table 3 Changes to communication framework when a child has a life-threatening condition

Change	Rationale for change
All instances of parent(s) changed to caregiver(s)	Caregiver is a more recognised term and biological parents may not always bring child(ren) to appointments
Prepare Yourself: ► for the potential emotional reaction of family ► for difficult questions a child may ask and how you will answer/handle these	These are emotionally demanding conversations for HCPs, but it is not widely recognised across healthcare systems. Peer support may not be offered or available
Prepare information: ► Identify who is the decision-maker within the family network; can they join the consultation	Important to acknowledge potential hierarchy within family and identify who has autonomy to make decisions about treatment. Decision-maker may not be the adult at the appointment
► Establish family's preferred language for the consultation and arrange a translator if needed. Prepare the translator about the rationale for the conversation and the implications for their role	English is common language of HCPs, but multiple local languages and dialects spoken. Costs for family if a translator is needed. Potential impact on what information is disclosed if a family member acts as translator. Translator may worry about translating upsetting information; may modify messages to make them more acceptable, but incorrect
► Identify relevant multidisciplinary team for ongoing management. ► Establish if you need to engage with other HCPs or teams who may have helpful packages	Much variation in ongoing care pathways, provision and geographical location of specialist services
Prepare environment: Setting a time and date in advance may facilitate the family bringing the most appropriate people to the meeting, including translators or decision-makers	Decision-makers play a key role in information communicated within families and treatment plans. Distances travelled to clinic may be long; families may need time to make plans
New section: *exploring spiritual, religious and cultural beliefs:*	
► Familiarise yourself with patient's community's beliefs regarding illness and/or death. Establish family's beliefs about illness and death	Traditional medicine is widely available and an important component of healthcare in some communities
► Caregiver(s) may be using alternative explanations (witchcraft) to explain the illness ► Give permission to open a discussion about the use of traditional medicine or healers ► Engage with traditional healers as may be needed for treatment/procedure to occur	Acknowledging alternative perspectives and beliefs about illness causality and treatment can facilitate the clinician–patient relationship. Engage families and encourage their consideration of 'western' medical interventions
Prepare the caregivers: ► Take time to establish caregivers' and patient's level of understanding; be respectful and avoid making assumptions ► Clarify caregivers' role and what you are asking them to do/not do	Variable levels of caregiver literacy and education. Important to check caregiver understanding if family and/or HCP are not conversing in their preferred language
Listen first: "What do you think is making you feel like this? What do you think is causing your symptoms?"	Opportunity to explore cultural, spiritual, religious beliefs that may conflict with medical explanation of illness
Choice of words (changed from 'Language'): ► Explain symptoms using basic medical words and clear, concrete concepts that are condition specific in order to prevent/dispel causality being attributed to the supernatural or magic ► Use clear words that the family will understand and avoid euphemisms or technical jargon. ► Familiarise yourself with children's developmental understanding of illness and death at different ages (see BPS document) ► Using a translator can be challenging, but translator's knowledge could be helpful to interpret family's non-verbal reaction	Another opportunity to explore cultural, spiritual or religious beliefs that may conflict with medical explanation of illness. Use language appropriate for the level of literacy Euphemisms risk misinterpretation, but some cultural groups have euphemistic words that are both clear and, crucially, respectful when talking about illness and death Workshop participants reported low levels of knowledge among peers regarding children's developmental understanding of illness Different cultural groups may have particular ways of expressing or avoiding showing their emotional reaction to news

Continued

Table 3 Continued

Change	Rationale for change
Sources of information: Ensure physical leaflets are available	Unreliable internet across many LMICs
Pay attention to emotional understanding: ► Children's understanding may need to be followed up in a further consultation ► Avoid phrases that assume an understanding of family's feelings	More directive phrases and prompts included due to the lack of specific training around direct and detailed communication with caregivers and children about children's illness
Ask child and caregivers what they have understood about what has been said:	
► If child explicitly asks "*Am I going to die*?" explore what they understand dying means (to clarify what question they are actually asking) ► "I've given you so much information today; I'm a bit worried I've not explained things clearly."	Offers an opportunity to clarify children's developmental, cultural, religious and spiritual understanding of death Responsibility for communication owned by HCP with aim of empowering caregivers to ask for clarification without fear of being impolite
New section: managing different opinions about how much a child should be told:	
► Explore caregiver's reasons for not wanting to tell their child about their diagnosis ► Discuss with caregivers how you will answer if child asks you a direct question about their diagnosis and/or prognosis ► Make plan about how to try and resolve difference of opinion; arrange a future meeting to revisit if needed ► Use colleagues for reflection, consultation and problem solving	Common for caregivers to be reluctant to tell children the diagnosis Important for HCPs to use peer support and expertise for these challenging conversations
Make a plan: ► Involve child in plan as much as possible; identify any opportunities for child to make choices or maximise their sense of control ► Give family a written care plan including short term achievable goals and sources of support. Provide multiple copies which they can give to different professionals involved in their care	Variability in HCPs' and caregivers' understanding of the importance of child-centred care Patient notes rarely on central database and internet access variable. May be limited opportunities for coordination between clinical teams at different geographical locations

"*There is a belief in some cultures that when there is a curse causing a particular illness, there are rituals to be performed… you [as a professional] don't really say it is wrong, you accept that it is true… it's very important to get into [the patient's] ideas of what they think should be done…After we know [the patient's] views, then you are able to come up with ideas about what should be done.*" [Participant 023, Uganda]

Participants felt raising the issue of communication with children was particularly challenging when their own or a caregiver's illness became incurable and death was inevitable. This was attributed to community views that death was 'a bad thing' and should not be spoken about. Professionals also felt that the family and community are focused on the child or adult patient 'getting better', rather than acknowledging and preparing for the end of life.

"*When it comes to death, death is regarded as something that needs to be respected. So you cannot say someone is going to die, because it's like you have given up on this person… you can't ever say that*" [Participant 008, South Africa]

"*Our culture doesn't talk about death, especially when it involves a child. It's taboo.*" [Participant 005, South Africa]

Sub theme 1.2: language barriers between families and the healthcare team

Many participants reported experiences of working with caregivers whose primary (and often only) language was different from that of the professional; this was identified as an obstacle to communication with caregivers about children's information needs. Participants reported that some local languages and dialects do not have an equivalent word for certain medical terms such as virus. Participants in South Africa discussed the importance of choosing a word for death that was both 'respectful' and unambiguous.

"Traditionally… you can't say someone is going to die. You have to choose words that mean 'passing away' … but you can't say 'dying'. They find it distressing. They prefer if you use more respectable words but in those words they know the message" [Participant 003, South Africa]

Table 4 Changes to communication framework when a caregiver has a life-threatening condition

Change	Rationale for change
All instances of parent(s) changed to caregiver(s)	Caregiver is a more recognised term
Prepare information: ► Establish who else in patient's family they want or do not want present for example, some male patients will not want female relatives present ► Identify who is the decision-maker within the family network; can they join the consultation ► Establish family's preferred language for the consultation and arrange a translator if needed. Prepare the translator regarding the rationale for the conversation and the implications for their role in translating ► Identify relevant multidisciplinary team for ongoing management ► Establish if you need to engage with other HCPs or teams who may have helpful packages	Important to acknowledge cultural norms about gender roles and responsibilities. Important to acknowledge potential hierarchy within family and who has autonomy to make decisions about treatment. Decision-maker may not be at the appointment. Patients may have children living in different households. English is common language of HCPs, but multiple local languages and dialects spoken. Costs for family if a translator is needed. Potential impact on what information is disclosed if a family member acts as translator. Translator may worry about translating upsetting information; may modify messages to make them more acceptable, but incorrect Much variation in ongoing care pathways, provision and geographical location of specialist services
Prepare environment: Setting a time and date in advance may facilitate the family bringing the most appropriate people to the meeting, including translators or decision-makers	Decision-makers play a key role in information communicated within families and treatment plans. Distances travelled to clinic may be long; families may need time to make plans
New Section: exploring spiritual, religious and cultural beliefs:	
► Familiarise yourself with patient's community's beliefs regarding illness and/or death. Establish the family's beliefs about illness and death ► Caregiver(s) may be using alternative explanations (witchcraft) to explain the illness ► Give permission to open a discussion about the use of traditional medicine or healers	Traditional medicine is widely available and considered as an important treatment in some communities. Acknowledging alternative perspectives and beliefs about illness causality and treatment can help facilitate the clinician–patient relationship and negotiation of what information about the illness is communicated to children in the family
Explore caregiver's views about talking to their children:	
► Establish barriers and caregiver's fears about talking to children ► May be helpful to share the experiences of other caregivers who have faced similar dilemmas about talking to their children ► Concerns of patient who has property and wealth ► Consider how patient may contact children from different households who might be able to practically help ill patient ► Cultural differences may make it difficult to understand the family's reaction; potential to use translator's knowledge to interpret the family's non-verbal reaction	Stigma about illness may be an additional concern for caregivers about sharing diagnosis with children Patients may have children living in different households with cultural expectations about how property or wealth divided if they died Practical support could be available from other members of family Different cultural groups may have particular ways of expressing or avoiding showing their emotional reaction to news
Choice of words (changed from language): ► *Consider use of drawings* ► *Encourage caregivers to use clear language and avoid euphemisms or technical jargon or words that could be misinterpreted. Explain symptoms using basic medical words and clear, concrete concepts that are condition specific in order to prevent/dispel causality being attributed to the supernatural or magic* ► *Encourage caregivers to prepare children who are at boarding school for changes in appearance of caregiver in advance*	High levels of caregiver and child illiteracy. Challenge of identifying written resources in appropriate language or access to written resources due to illiteracy. Euphemisms risk misinterpretation but some cultural groups have euphemistic words that are both clear and, crucially, respectful when talking about illness and death Another opportunity to explore cultural, spiritual or religious beliefs that may conflict with medical explanation of illness Many children may attend school at distance from family home, with relatively infrequent visits
Reassurance for caregivers that discussion will not cause more problems	

Continued

Table 4 Continued

Change	Rationale for change
► Explain that clearly telling a child what the illness is may prevent the child from unnecessarily blaming the caregiver for example, HIV, or wrongly attributing the illness to witchcraft or magical thinking ► If necessary, explain benefits for children in preparing them for caregiver's death	Improving child's understanding of illness can reduce stigma and/or self-blame. May be short time period between consultation and death; limited opportunities for future discussions to update children's knowledge regarding illness progression
Preparing caregivers for common questions: Alert caregivers that children may show their worries through prayer or drawing Encourage caregivers to observe child's play and then explore the themes that emerge Sharing the diagnosis with family members may bring up issues of succession	Family social hierarchies mean that children may not routinely feel able to ask adults questions Succession potential obstacle for caregivers in deciding whether to disclose a diagnosis
Future thinking: ► Explore the importance of children's teachers and school. Support from their religious community may also be needed. Identify who is a trusted source of information for the patient and their family; may be helpful to involve this person(s) from their community ► Consider encouraging the patient to start writing a will and planning for the child's future school fees. Could talk with the child about their future plans and identify a suitable mentor together ► For very young children, encourage the caregiver to put together a memory book	Caregivers may not consider that teachers could have an additional role as an emotional support for children. Religious faith is central to many communities. Limited opportunities for professional prebereavement support for caregivers and children Financial planning and succession arrangements are complex when dependent children may live in multiple households. School fees are a significant financial commitment for many families. Limited opportunities for professional pre-bereavement support

Although some clinics and hospitals were reported to have translators available, the additional costs involved were prohibitive for many patients if another person needed to be brought in to assist with translation. Translators are usually nurses who assist where able, and may have their own level of discomfort with the discussion. As a result, professionals stated they were not sure if the family had understood the diagnosis, prognosis and treatment options for the child or caregiver. Professionals described how other family members, often unaffected (well) children, might take on the role of interpreter during the consultation. In these scenarios, some professionals limited the information they disclosed about the illness during the consultation to avoid causing upset to the child who is interpreting.

"*If you use an interpreter within the family, you are not certain that what you've said is being translated directly to the other person. It goes through the filter of someone else*" [Participant 031, Uganda]

Participants also identified the 'crucial role' of interpreters who were able to facilitate communication both practically (in terms of translating from one language to another) but also in terms of the wider cultural context of the conversation.

"*Hopefully with a good translator what gets said will be culturally appropriate and they will use the appropriate euphemisms rather than confusing euphemisms, but just to be aware that things will get lost in translation.*" [Participant 002, South Africa]

"*The translator becomes a cultural broker, as well as a linguistic tool*" [Participant 012, South Africa]

Sub theme 1.3: emotional and practical challenges for professionals to providing family-centred care

Workshop participants described the emotional challenge of working with caregivers or children with a life-threatening condition. Often, professionals felt that there were either no or very few opportunities to reflect on the emotional impact of this work with colleagues due to the 'overwhelming' number of patients. Professionals described feeling ill-equipped to appropriately support families experiencing serious illness, which impacted on their confidence to work with these patient groups. This included how and when to raise discussions about children with caregivers. Participants highlighted that clear guidelines on how to start this conversation with caregivers would be beneficial for clinicians, both practically and emotionally.

Some participants felt that they were in 'the minority' among their colleagues in wanting to consider children's emotional needs when they or a caregiver had a life-threatening condition, describing the feeling as 'swimming against the tide'. Participants described feeling 'isolated' and 'unsupported' as their views were not shared by the wider professional culture and therefore it

was challenging to try and advocate for honest and clear communication about life-threatening conditions.

"*The concept that you need to take a family history and understand more about the family and whether there are children is important, but when [medical students] present that information to consultants, they are told.… 'get to the point' and 'move on'… it's not being role modelled.*" [Participant 011, South Africa]

Perceptions of the discordance between their own beliefs and those of their colleagues about communication were compounded by time pressures due to the large numbers of patients waiting to be seen.

"*The structural factors that make this so difficult… trying to persuade colleagues and persuade yourself that the best thing to do is to use the time communicating that impact on family, when there's a long queue of people, some of whom will not get seen during the day… when there are not enough staff…*" [Participant 007, South Africa]

Participants generated a number of practical suggestions that might lead to a broader understanding among colleagues about the rationale for communication with children about their own or a caregiver's illness, such as lobbying professional societies to include communication with children as a topic for medical exams. The participants also considered ways in which community understanding about communication with children might be enhanced, with the hope that this might also encourage patients or caregivers to raise the issue of what to tell children with their healthcare team. Faith leaders and social media were identified as structures which could be harnessed to promote the importance of communication. These messages could be reinforced through posters and printed materials in hospitals and clinics.

"We need something on our desk to help us take us through what to say to our patients.…Posters in the waiting room might get patients to think about even bringing this up in appointments." [Participant 019, Uganda]

Theme 2: obstacles to telling children about the reality of a life-threatening condition

Most participants described working with caregivers who believed not telling children about the reality of their own or a caregiver's life-threatening condition would protect children from pain and upset. They said that some caregivers felt there was 'less need' to tell younger children (<12 years old) about a serious health condition in the family as they would not have the capacity to understand the situation. Some professionals believed it was important to tell caregivers that withholding the truth from children about their own or a caregiver's illness was 'not in the child's best interest' as they were likely to be aware or know 'something is wrong'. However, they often described situations where caregivers were 'adamant' the children were not to be informed about their own or a caregiver's illness; caregivers were described as 'shutting down the conversation' when the professional raised the topic of telling children. Other professionals reported that caregivers believed telling children they were going to die from their illness would cause the child to 'lose hope and die quickly' and so would not disclose the seriousness of their condition.

"Patients say "I don't want my child involved in the discussion, you are not allowed to tell my child."" [Participant 020, Uganda]

Financial constraints were seen as an additional obstacle for families communicating with a child about their life-threatening condition. Caregivers were faced with needing to make choices about spending money on treatment, especially if the illness was incurable and death was expected and they had other dependent children. Participants felt that caregivers often decided not to tell the children the reality of the diagnosis if the anticipated cost of ongoing treatment (which might be needed for many years) and associated travelling would be prohibitive for the family.

"Families…they have to decide, to choose, which children to spend their money on. If a child is going to die, they have to decide how to spend their money." [Participant 015, South Africa]

Communication within the family about a caregiver's life-threatening condition could be complex when a father had children living in different households. Decisions about sharing the news of their approaching death with multiple partners and children was influenced by the potential for 'claims' on the deceased's estate. Participants' awareness of this situation had made it difficult for them to encourage caregivers to share information about the illness with their family.

"*For wives who have children [of a man who is ill] they may be thinking in terms of succession, maybe their property. And they may be thinking, if I tell the other children, they may want or start planning for the property.*" [Participant 019, Uganda]

Most participants reported that one or several members of the extended family is usually designated as the 'decision-maker' (responsible for deciding and agreeing treatment decisions for children or caregivers with a life-threatening condition); these are often the 'elders' within a family. Professionals described scenarios where the decision-makers were not present at appointments which often limited or delayed decisions about a child or caregiver's treatment. In addition, the absence of the decision maker also inhibited decisions being made about what children should be told about their own or a caregiver's health condition.

"The parent/carer may not be the decision maker in the family—there is no individual autonomy" [Participant 006, South Africa]

Changes to the communication frameworks

Following part I of the workshop (discussions regarding the experiences of the professionals in clinical settings in South Africa and Uganda), an iterative process of discussion and refinement (part II) was used to make adaptations to previously published communication frameworks[3 4] to facilitate their use in South Africa and Uganda. The changes (and associated rationale) to the frameworks are reported in tables 3 and 4. The changes predominantly represent additions (unless otherwise stated) to the previously published frameworks; sections from these[3 4] which remained unchanged are not reproduced in tables 3 and 4.

DISCUSSION

Healthcare professionals across the globe face multiple challenges in supporting caregivers to consider why and how they could communicate with children about a life-threatening condition. These include the high volume of patients presenting in healthcare services which necessitates priority setting for the content and duration of consultations. Furthermore, high levels of 'burnout' in professionals has been reported in sub-Saharan Africa.[25] Healthcare professionals must also consider families' specific cultural needs[17] and some parents believe that telling children will have an adverse impact on their child's emotional health.[3 4 26] The results of this study highlight the importance of healthcare professionals exploring families' beliefs and preferred language to talk about illness, medicine and death during a patient's appointment. Establishing a family's cultural, spiritual and religious understanding about using other (traditional) treatment methods alongside Western medicine could help promote a mutually respectful relationship between the clinician and the family. Healthcare professionals should recognise how in some cases, stigma may influence family-centred care within a family and their community; the importance of this is also emphasised by a recently proposed global framework for paediatric cancer communication research.[27]

A trusting relationship between the healthcare professional and the family could facilitate opportunities for the clinician to start a conversation with the caregivers about how best to support their children when a family member has a serious illness. Identifying family dynamics is important for all clinical consultations but engaging the family decision-maker/s is particularly important in sub-Saharan Africa.[28 29] The decision-maker's attendance may be key to initiating communication within the family about telling children about the diagnosis of an illness in themselves or others. In addition, recognising the potential influence of the adult patient's family circumstances (eg, children living in multiple households) or the family's financial situation (whether treatment is financially viable) is crucial to understand a family's position about whether to communicate with children about illness.

A study in South Africa found that caregivers want information from their clinical teams on how to talk to children about illness as well as guidance on how to speak to other children in their family about a sick child.[9] Yet, we report in this paper that healthcare professionals expressed their perceived professional isolation about promoting family-centred conversations with their colleagues. Enhancing clinicians' knowledge about the benefits of encouraging effective communication with children regarding serious illness could help health systems and services recognise the importance of this task. This may involve embedding specific training about communication with children within professional training courses and examination structures. However, it is important to consider the capacity of health systems and services as well as the enormous caseloads and time pressure on healthcare professionals which can limit opportunities to initiate family-centred conversations. This highlights the need for clear evidence-based guidelines to ensure that communication with children can be integrated into regular consultations without adding additional burden to healthcare professionals. It is important to recognise that in the healthcare contexts of South Africa and Uganda, implementation of the amended frameworks may be aspirational.[3 4] It is essential to ensure such guidelines take into account the differences in diverse racial and ethnic groups. Cultural considerations were discussed during workshops with professionals (described here) resulting in adaptations to previously published frameworks.[3 4] Consensus within the group from a range of professionals will increase successful implementation into South African and Ugandan contexts. However, evaluating the new guidelines in terms of usefulness and applicability in South Africa and Uganda needs to be a focus in future studies.

Increasing families' and healthcare professionals' understanding of the benefits of communication with children about a life-threatening condition in the family will also be critical to promoting and embedding these conversations into routine care. These benefits include lower behavioural difficulties for children, better adult adherence to treatment and family well-being.[3 4] Furthermore, families and professionals may benefit from information about the evolution of children's developmental understanding; even very young children notice when a caregiver is unwell, with research indicating that parents often underestimate children's comprehension of illness.[3 4] Enhancing community-level awareness about children's understanding of illness and the importance of communication could be fostered through existing structures such as faith groups and promotional materials (eg, posters and social media). Sharing information with traditional healers about children's developmental understanding and the benefits of effective communication might also contribute to reducing some of the identified obstacles to these conversations.[30] Ultimately, facilitating effective communication with children about life-threatening illness in the family can have long-term

consequences for psychological well-being and family functioning.[3 4]

Strengths and limitations

The workshops were conducted in English and participants were asked to comment on the frameworks written in English. The study did not include participants who were not fluent or confident in English; this may have excluded community and lay healthcare workers who play a significant role in healthcare services. A strength was that the participants in the workshops were from a range of healthcare professional backgrounds and drawn from different regions in South Africa and Uganda. However, further work will be required to consider the applicability of the frameworks to different countries or regions of the continent. The adapted frameworks are intended for use in facilitating communication about any disease which potentially enhances their utility within the healthcare system. The workshops comprised a number of elements, which were attended by all participants, including embedded focus group discussions, break out rooms and consensus discussions. In combination with researcher field notes, these provide a rich source of data beyond what might be achieved by a focus group or consensus group alone.

CONCLUSION

There are many factors that impact parents and children communication about serious illness. Healthcare professionals are faced with challenges in facilitating these conversations. Establishing cultural beliefs and understanding family dynamics is crucial in these consultations as well as managing the different opinions about communicating with children about serious illness in different contexts. Workshops with healthcare professionals in South Africa and Uganda generated adaptations to published communication frameworks to improve effective communication about illness with children. These new guidelines may help to tackle some of the communication challenges in this context and improve communication about serious illness between families and healthcare professionals.

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