

Adaptation and cognitive testing of the African Children's Palliative Outcome Scale (African C-POS) with children and young people living with serious illnesses and their caregivers

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Abstract

Background

Children and their families attending palliative care have not been able to benefit from the use of person-centred outcome measures due to the lack of a valid tool. A key step in tool development and validation is cognitive interviewing, especially for children, for whom appropriate language and format is critical.

Aim

To adapt the African Children's Palliative Care Outcome Scale (African C-POS) and establish its comprehensibility, comprehensiveness, relevance, and acceptability.

Design:

Stage 1: Co-design workshops to refine the C-POS. Stage 2: 3 rounds of cognitive interviews were conducted using 'think aloud' and verbal probing techniques.

Setting/participants:

Health care providers, academics and commissioners, Children 7–19 years old with life-limiting conditions and parents/carers of children 0–19 years with a life limiting condition, were recruited from three tertiary care centres in Uganda.

Results

Stage 1: Drawing on existing evidence of priority needs, a stakeholder workshop developed seven versions from the original African C-POS. We added three items to address conceptual gaps on spiritual and psychosocial concerns and to address developmental and cognitive age differences of the children. Response scales were revised to 3 levels for children aged 5–7 years, and 5 levels for other age groups. Stage 2: Cognitive testing, 27 children, 19 proxy family/caregivers and 14 proxy health professionals across the 7 C-POS versions participated in 3 interview rounds. Content, recall times, and length were acceptable.

Conclusion

Co-design and cognitive interviewing enhanced the face and content validity of the African C-POS. The current versions address the developmental/cognitive age, symptoms, and concerns of children living with life-limiting conditions.

Plain English summary

Why is this study needed?

- A lack of robust outcome measures for children's palliative care hampers children's palliative care service development.

What is the key problem/issue/question this manuscript addresses?

- Measuring outcomes is important for driving quality improvement in paediatric palliative care.
- There is a lack of evidence on psychometric properties for the novel African children's palliative care outcome scale (African C-POS).

What is the main point of your study?

- This paper provides seven versions of the children's palliative care outcome scale with good face and content validity.
- The current versions address the developmental/cognitive age, symptoms, and concerns of children living with life-limiting conditions.

- **What are your main results and what do they mean?**

The current versions of the African Children's palliative care outcome scale have robust psychometrics properties and can be used to drive person-centred care and quality improvement in children's palliative care.

Background

Worldwide, more than 21 million children and young people (hereafter "children") who live with life-limiting illnesses could benefit from palliative care every year.(1) Over 97% of these children live in resource-limited settings where patients commonly present with advanced disease with fewer curative options.(2)

Children with life-limiting and life-threatening illness face complex and distressing multidimensional symptoms and concerns(3, 4), which can be alleviated through palliative care(5). Palliative care is recognised as an essential health service within Universal Health Coverage and there is some evidence that it improves quality of life among children and their caregivers(6). However, the development of palliative care services remains inadequate.(7)

A lack of robust, psychometrically sound outcome measures has been cited as a barrier to the development and evaluation of children's palliative care services.(7) Preliminary evidence suggests that the use of outcome measures in routine practice improves outcomes for children(8). However, existing paediatric quality of life tools for this population are not appropriate in the context of palliative care.(9, 10) This lack of outcome measures is further compounded by inconsistency in the way outcomes are defined in children's palliative care.(11)

The African CPOS is a novel outcome measure specifically developed for children's palliative care.(12) Although the initial African C-POS tool found some good, psychometric properties it required further refinement to strengthen its validity and reliability for use in children's palliative care.(13)

The original African C-POS was a single measure with self- and proxy-report versions measuring the construct of symptoms and concerns in children with life-limiting conditions (0–17 years) and their families. It is underpinned by the World Health Organization definition of paediatric palliative care.(14) Ideally, questions about the child should be answered by the child; however, children may be unable to self-report for several reasons, such as age, limited cognitive ability to engage, or advanced disease. In such instances, the family caregiver – or, where there is no primary caregiver, a health professional or other care provider - may provide a caregiver-proxy report.(15, 16)

The African C-POS was developed using multi-national primary data from children, caregivers, and healthcare professionals across Africa(4), together with evidence from a systematic review of primary outcomes of concern in

the population(3). The development of C-POS UK version has largely been informed by the African C-POS(17) and it provides further learnings to inform the refined the African C-POS.

This study aimed to refine the original African C-POS in response to the deficits revealed in psychometric evaluation, and to undertake cognitive testing of the revised version. The adaptation methods reported here were informed by data from its implementation(13), a review of appropriate design for health outcomes measurement design with children(18), and the cognitive interview methods of the C-POS developed in the United Kingdom.(17)

Methods

Study design

The mixed-methods design included: Phase 1) two co-design stakeholder workshops to refine the African C-POS and Phase 2) a cross-sectional cognitive interview study following COSMIN and Rothrock guidance.(19, 20) This study is reported according to the Cognitive Interview Reporting Framework.(21) The design and conduct were informed by guidance on best practice for the engagement and involvement of children and young people in palliative care research.(22)

The African C-POS

The African C-POS was developed following COSMIN taxonomy best practices and guidance.(23) It also aligns with the Rothrock guidance on continuous improvement in outcome measure development.(20) The African C-POS previously underwent a psychometric evaluation which showed several limitations and recommendations were made to address developmental age differences, conceptual gaps, revision of items that were confusing or sensitive to developmental age differences, and to revise response levels.(22)

Setting

The study was conducted at two tertiary hospitals and a homecare service in Kampala, Uganda.

Inclusion criteria for the co-design workshops

- Adults engaged in children's palliative care through clinical care (any profession), or research.
- Children living with life limiting illness aged 7-19 years living with a life-limiting illness
- Parents/ carers of children 0–≥19 years with a life-limiting condition who could comprehend and speak English, Luganda, or Runyankore-Rukiga.

Exclusion criteria:

- Children unable to participate in the interview procedures, either independently or with caregiver support.

Sampling criteria for the co-design workshops and cognitive interviewing

Purposive sampling was used to ensure heterogeneity in cognitive age of the children and the diagnostic groups commonly seen in palliative care, in the designation of professionals engaged in care delivery, and in the age and role of caregivers.

Data collection

1)Co-design workshops.

Key decisions were guided by: existing evidence enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people (specifically recall period and response scale format)(18); evidence for needs of children with life-limiting illness(3); qualitative data from children in Africa with life-limiting illness(4); recommendations for refinement from the psychometric evaluation of the original C-POS(24)

Workshops were conducted in mixed groups with designated support for the children. Presentations at the workshop summarised the nature and purpose of outcome measures, existing evidence on needs and measurement, and the current version of the African C-POS. All presentations were delivered in lay language to ensure comprehension and meaningful participation following best methods in paediatric research.(22)

Group work was used to appraise the breadth and relevance of constructs covered, identify any missing items (drawing on the prior qualitative data and the psychometric evaluation), item importance and interpretation, appropriate content by version, response levels (drawing on the systematic review), format, length, and layout. Consensus decisions on the proposed revised versions were reached and consequently circulated for cognitive testing and further comment.

2) Cognitive testing.

Following the adaptation, psychometric methods literature recommends that the revised versions undergo further cognitive testing to assess their relevance, comprehensiveness, comprehensibility and appropriateness of response scales, among the population the measure is meant for(25). The interviews were conducted by two female palliative care providers with experience in qualitative research (EN1, EN2). Three rounds of cognitive interviews were conducted, enabling the revision and retesting of the tools. Areas of investigation were based on Tourangeau's four-stage model of survey response – comprehension, retrieval, judgement, and response.(26) Issues identified were classified using Willis's coding system for questionnaire problems.(27)

A final workshop was then held to review the findings from the cognitive interviews and make edits to the measure as appropriate.

Each of the African C-POS versions were cognitively tested with at least five participants. Three iterative rounds of interviews were conducted, with any amendments undergoing further cognitive testing involving at least four new interviewees per version. All interviews were conducted face-to-face. Children were interviewed individually but were permitted to have their parent/caregiver present if they requested it.

Interview procedure

The procedure for interviewing followed several key steps:

1. Introduction and recruitment: Clinical teams introduced the research team to the children and the caregivers in a face-to-face interaction at the health facilities. Then the researchers gave them written information about the study in their preferred languages.
2. Consent and assent: Informed consent was obtained from caregivers and assent from children who wished to participate.
3. Orientation: Participants were debriefed on the cognitive interviewing process and the "think aloud" technique and each completed a short practice session before the main interview.
4. Interview: Cognitive interviews were conducted using a structured questionnaire that included probes regarding clarity of item wording, recall, and response format.
5. Evaluation: Participants provided feedback with comments on overall acceptability, relevance, comprehensiveness of the measure, and burden of time and exertion for completion of the measure.

6. Children were interviewed alone where possible but were also allowed to bring in their caregivers if they wished. For interviews with caregivers and health workers no other person was in the interview room besides the researcher and the respondent

Prior to each interview, participants completed the consent process and a short demographic questionnaire. Interviews were conducted using the “think aloud” technique alongside concurrent verbal probing.(28-30) A topic guide was used to ensure the use of pre-scripted probes regarding item wording, recall, and response format. After all C-POS items had been cognitively tested, participants were asked questions regarding the acceptability, relevance, and comprehensiveness of each item, whether any items were inappropriate and should be left out, whether any important items were missing and should be added to the C-POS, and whether the number of items and time taken to complete the measure was acceptable. Spontaneous probes were used to further explore any hesitations or difficulties.(31)

Version selection for child participants was guided by developmental age, allowing the child (with healthcare professional and/or caregiver) to choose the most appropriate version. Previous work highlighted challenges in ascertaining at what chronological/developmental age children can reliably use longer recall periods and more complex response formats.(18) The use of emojis to anchor response options was informed by evidence from previous research(32) with a smiling emoji representing the most positive outcome for each item. All interviews were audio recorded (see figure 1).

Cognitive interview data analysis

Data were analysed by two members of the study team (EN1, EN2), with codes being reviewed by the whole study team at scheduled meetings. Data analysis followed the five stages of Framework Analysis, as recommended by the National Centre for Social Research for analysing cognitive interview data: familiarisation, constructing a thematic framework, indexing and sorting, charting and mapping/ interpretation.(26, 27, 30, 33) Data from all interviews responses were summarised in a single dataset using Microsoft Excel. A matrix was created for each C-POS item, with each row representing an individual participant and each column representing an area of investigation.(26, 27, 30, 33).

Themes from the data were indexed onto an expanded matrix informed by Tourangeau’s model of the cognitive response process and Willi’s framework for identifying and classifying problems with questionnaires.(34) All identified issues and proposed revisions to the tool were discussed by the research team and consensus decisions were made regarding changes to item wording, structure, or response format. Study participants did not give additional feedback to the findings.

Ethics

Ethical approval to conduct the study was given by Mildmay Uganda Research and Ethics Committee (REF-0107-2023/2027). Written informed assent and consent was obtained for the study participants as appropriate. Information sheets were provided in age- appropriate formats (for the children) and in all relevant local languages. Data were stored on password protected computers and servers. Data were collected between 2023-2025.

Results

1) Co-design workshop

Participant characteristics

The adaptation co-design stakeholder workshop included 47 participants (3 academics were medical doctors), comprising nurses ($n = 15$), general doctors ($n = 5$), teen leaders ($n = 4$), psychologists ($n = 3$), academics ($n = 3$), commissioner/ policy makers ($n = 3$), young people living with life limiting or life-threatening illnesses (members of the project child advisory council) ($n = 3$), chaplains ($n = 2$), social workers ($n = 2$), paediatricians ($n = 2$), data scientists ($n = 2$), child play therapists ($n = 2$), parents /informal caregivers ($n = 2$), counsellor ($n = 1$), storyteller ($n = 1$), clinical officers ($n = 1$). Building on the existing presented evidence and the UK CPOS development process,(17) from the initial single measure (with self-report and proxy report versions), seven African C-POS versions were developed to reflect age/ developmental differences in children and to apply an appropriate recall period.

Consensus was reached on the content provided in Table 1 and on the development of the seven versions of the African C-POS. The versions explored the same core concepts with simplified language used for younger children. Child versions were named after birds (chosen by the child advisory council) to reduce any stigma that might arise from using chronological age labels, particularly for children with developmental delays (see Table 1).

Table 1
The content of the African C-POS measure -revised version

1	African C-POS Version	Recall period	Type of response scale
	Flamingo for 5–7 years development stage	Yesterday or today	Three-point response scale
2	Crested Crane for 8–12 years development age	Past seven days	Three-point response scale
3	Peacock for 13–19 years of development age	Past seven days	Five-point response scale
4	Parent proxy A for non-verbal children below 2 years	Past seven days	Five-point response scale
5	Parent proxy B for children above 2 years but are not able to self -report	Past seven days	Five-point response scale
6	Health professional proxy A – for children below 2 years and have no family caregivers – health professionals report on their behalf	Past seven days	Five-point response scale
7	Health professional proxy B – for children above 2 years, but are not able to self- report and have no family caregivers – health professionals report on their behalf	Past seven days	Five-point response scale
	Child symptom and concern items (self-reported or proxy-reported)	Parent/carer items	
	Pain	Information	
	Other symptoms	Family worry	
	Feeding	Help and advice	
	Worry	Family share how they feel	
	Happy	Help and advice to plan for the future	
	Do things they enjoy	Access emotional support	
	Do things you usually do	Information about child's illness	
	Share feelings	Family confidence	
	Being able to ask questions	Getting enough sleep	
	Sharing feelings		
	Felt at peace		
	Hope		

Decision: It was decided to use the same recall periods and response options as those used in the C-POS:UK (based on evidence from the systematic review on measure design for children)(18) and to subject these to cognitive testing.

2) Cognitive Interviews

For the three rounds of cognitive interviews, a total of 29 children, 19 proxy reporting caregivers, and 14 proxy reporting from health professionals was reached. One of the caregivers approached declined participation. Interviews lasted between 45–60 minutes. The demographic characteristics of participants are presented in Tables 2.

Table 2
Demographics of cognitive interview participants – children (n = 29)

Cognitive interview round	Round 1 (n = 16)	Round 2 (n = 6)	Round 3 (n = 7)	Overall (n = 29)
Gender				
Male	8	3	4	15
Female	8	3	3	14
Highest level of education				
No education	2	1	0	3
Primary school	9	2	4	15
Secondary school	5	3	3	11
Religion				
Roman Catholic	5	2	4	11
Muslim	4	2	2	8
Pentecostal/Anglican	7	2	1	10
Diagnosis				
Cancer	7	5	4	16
HIV/AIDS	2	0	0	2
Sickle cell	4	1	3	8
Congenital abnormalities	1	0	0	1
Neuro-cognitive	2	0	0	2
Name of health facility				
Mulago Hospital	14	4	6	24
Mildmay Hospital	1	2	0	3
Kawempe Home Care	1	0	1	2
C-POS version used				
Crested crane i.e. Development age 13–19 years	4	2	2	10
Flamingo i.e. Development age 5–7 years	5	2	2	9
Peacock i.e. Development age 8–12 years	7	2	3	12

In Table 3, we present the African C-POS versions, the response scale options and number of cognitive interview participants.

Table 3
Number of cognitive interviews conducted by type of C-POS version

Version	Respondent	Number of questions	Recall period	Response format	Total number of participants	Number of cognitive interview rounds	Number of participants final versions tested in
Flamingo 5–7 years	Child With a development age of 5–7 years	11	Yesterday or today	Three - point Likert scale anchored with emojis	10	03	2
Crested crane 8–12 years	Child with a development age of 8–12 years	11	Past seven days	Five-point Likert scale anchored with emojis	09	03	2
Peacock 13–19 years	Child with a development age of 13–19 years	11	Past seven days	Five-point Likert scale anchored with emojis	10	03	3
Parent/carer < 2 years	Caregiver to a child less than two years	18 (11 about the child and 7 about the family)	Past seven days	Five-point Likert scale	09	03	2
Parent/carer Above 2 years	Caregiver to a child above 2 years and non-communicative older children	18 (11 about the child and 7 about the family)	Past seven days	Five-point Likert scale	10	03	1
HCP version A	Health worker	18 (11 about the child and 7 about the family)	Past seven days	Five-point Likert scale	07	03	2
HCP version B	Health worker	18 (11 about the child and 7 about the family)	Past seven days	Five-point Likert scale	07	03	2

Proposed revisions from cognitive interviews

Following the first round of the cognitive interviews, minor revisions to the wording were proposed to improve clarity and comprehension of items, including adding an explanation for the changes proposed, for example:

- Item 1 Pain: Replace the word “hurt” with “pain”.

- Item 2 Problems with your body other than pain: Include some examples of physical symptoms.
- Item 3 Feeding and eating: Use the phrase “feeding” for children aged 0–7 and “eating” for children aged 8–19 years.

“Are you asking about my appetite or being able to eat the food I enjoy eating?” (Child 02, 15 years)

- Item 4 Worry and anxiety: Remove the word “anxiety” because it is difficult to understand.

“I do not understand the term ‘anxiety’.” (Child 04, 8 years)

“I do not understand what ‘anxiety’ is.” (Caregiver 02, child aged 2 years)

- Item 6 Do things you enjoy: Include an option of *Not applicable* and change the ordering of the questions. Start with things you usually do and then things you enjoy.

“With the current ordering, it looks like the item on ‘things you enjoy’ and ‘things you usually do’ are the same. Maybe we change the order and see how that works.” (Health worker, 08)

Second co-design workshop

Following the completion of the second round of cognitive interviews, feedback was gathered and discussed at the second key stakeholder workshop. The meeting was attended by nurses ($n = 15$), young people ($n = 6$), doctors ($n = 5$), psychologists ($n = 3$), academia ($n = 3$), chaplains ($n = 2$), paediatricians ($n = 2$), data scientists ($n = 2$), story teller ($n = 1$), counsellor ($n = 1$), play therapist ($n = 1$), commissioner ($n = 2$), parents ($n = 2$).

The following changes were made:

- Item 9 Questions about illness: Remove the word, ‘opportunity’ and ask about being able to ask questions about illness.

“The phrase opportunity is difficult to understand.” (Child, 17 years).

These changes were tested in the third round of cognitive interviews.

At the third round of interviews there were no suggested changes to the structure, included questions, or question order. The final version of the C-POS includes seven versions. The changes made are presented in Table 5.

Table 5
Main findings from cognitive interviews with children and young people and caregivers

African C-POS item number	African C-POS item	Comprehension	Retrieval	Judgement	Response	Changes made to response format	Changes made to African C-POS item
1	Hurt (5-7years Pain (8-12 years and 13-19 years	The word hurt was confusing and ambiguous. Good comprehension, but children preferred to have it answered in terms of intensity and impact on daily living .	The 5-7 years could recall the past three days The 8-12 years and 13-19 years could recall the past seven days	Children and caregivers could integrate thoughts into the response	The use of cue cards with emojis was liked by children aged 5-7 years and 8-12 years. 5-7 years could use the 3-point response scale 8-12 could use the five point scale 13-19 years could use the five-point scale	None	Question phrased to focus on intensity and impact on activities of daily living. Removed the phrase “can you” as it was viewed as commanding.
2	Other problems with your body	The question is difficult to understand without examples of other body problems. The word affected is difficult for all children to comprehend	The 5-7 years could recall the past three days The 8-12 years and 13-19 years could recall the past seven days	Children and caregivers could integrate thoughts into the response	5-7 years could use the 3-point response scale 8-12 could use the five point scale 13-19 years could use the five-point scale	Remove the word “ feeling sick” and include some examples of physical symptoms.	Question phrased to emphasise other physical body problems other than pain, examples included lack of appetite, vomiting and body weakness. Removed the phrase “can you” as it was viewed as commanding. Rephrase the question to remove the

African C-POS item number	African C-POS item	Comprehension	Retrieval	Judgement	Response	Changes made to response format	Changes made to African C-POS item
							word affected.
3	Feeding	Comprehension was difficult, adolescents felt the term feeding was more appropriate for children below the age of 8 years.	The 5–7 years could recall the past three days The 8–12 years and 13–19 years could recall the past seven days	There problems integrating thoughts into an appropriate response			Use the word Feeding (5–7 years) Use the word Eating (8–12 years and 13–19 years)
5	Cried	Comprehension was difficult because children may cry for some many reasons. Children aged 8 and above noted that	It was difficult to recall how often the children cried	It was difficult for children and caregivers to integrate thoughts into their responses	The use of cue cards with emojis was liked by children aged 5–7 years and 8–12 years. 5–7 years could use the 3-point response scale 8–12 could use the five point scale 13–19 years could use the five-point scale		Item was dropped because it was confusing and difficult to make sense of.
6	Play	Comprehension was okay but children noted that what was important was being able to	The 5–7 years could recall the past three days	Children and caregivers could integrate thoughts	The use of cue cards with emojis was liked by	None	Change from felt like playing to being able to play

African C-POS item number	African C-POS item	Comprehension	Retrieval	Judgement	Response	Changes made to response format	Changes made to African C-POS item
		play not to feel like playing	The 8–12 years and 13–19 years could recall the past seven days	into the response	children aged 5–7 years and 8–12 years. 5–7 years could use the 3-point response scale 8–12 could use the five point scale 13–19 years could use the five-point scale		
7	Worry and anxiety	Comprehension was good for worry but the phrase “anxiety” was not well understood.	The 5–7 years could recall the past three days The 8–12 years and 13–19 years could recall the past seven days	Children and caregivers could integrate thoughts into the response	5–7 years could use the 3-point response scale 8–12 could use the five point scale 13–19 years could use the five-point scale The word past week was not clear to many	Change past week to past seven days for 8–12 and 13–19 years. Past three days for 5–7 years.	Remove the word Anxiety Removed the phrase “can you” as it was viewed as commanding.
8	Happy	Comprehension was good For the African C-POS Proxy A and African C-POS proxy B It was difficult to proxy report on feelings, it	The 5–7 years could recall the past three days The 8–12 years and	Children and caregivers could integrate thoughts into the response	No problems	Change past week to past seven days for 8–12 and 13–19 years. Past three days for 5–7 years.	None

African C-POS item number	African C-POS item	Comprehension	Retrieval	Judgement	Response	Changes made to response format	Changes made to African C-POS item
		made more sense to ask about appeared happy	13–19 years could recall the past seven days				
9	Do things you usually do	Comprehension was good	The 5–7 years could recall the past three days The 8–12 years and 13–19 years could recall the past seven days	Children and caregivers could integrate thoughts into the response	No problems	Change past week to past seven days for 8–12 and 13–19 years. Past three days for 5–7 years.	None
10	Do things you enjoy	Comprehension was good but four children and three caregivers thought it was quite similar to do things you usually do.	As above	As above	No problems	Change past week to past seven days for 8–12 and 13–19 years. Past three days for 5–7 years.	Change ordering Start with things you enjoy followed with things you usually do.
11	Information about illness	the word opportunity was difficult to understand	As above	As above	No problems	Change response options to reflect as much as wanted or less than wanted	Remove the phrase opportunity
12	At peace	For three children - comprehension was difficult	As above	As above		Change past week to past seven days for 8–12 and 13–19 years. Past three days for 5–7 years.	Include some probes as needed – for example what gives you meaning?
Family items							

African C-POS item number	African C-POS item	Comprehension	Retrieval	Judgement	Response	Changes made to response format	Changes made to African C-POS item
13	Family information	No problems	No problems	No problems	No problems	No problems	None
14	Family worry	No problems	No problems	No problems	No problems	No problems	None
15	Family help and advice	No problems	No problems	No problems	No problems	No problems	None
16	Family shared feelings	No problems	No problems	No problems	No problems	No problems	None
17	Access to emotional support	No problems	No problems	No problems	No problems	No problems	None
18	Family confidence	No problems	No problems	No problems	No problems	No problems	None
19	Family being able to sleep	No problems	No problems	No problems	No problems	No problems	None

Discussion

The current lack of outcome measures with robust psychometric properties is a recognised challenge in the development and evaluation of paediatric palliative services.(7) The African C-POS was developed in accordance with best practices for developing outcome measures(23), and is underpinned by a child-and-family-driven framework regarding symptoms and concerns.(4)

Main findings

The African C-POS also aligns with Rothrock's guidance on continuous development and improvement of outcome measures.(20) The C-POS response scale format, recall period, administration modality, and frequency of completion are also informed by best practices for enhancing validity, reliability, and participation in self-reported health outcome measurement.(18)

The involvement of children and young people in the development process was particularly valuable. It ensured that the study team considered their views, preferences, and what was important to them in terms of outcomes. For example, the identification of symptoms such as 'overeating' as a concern, as well as the intensity and impact of the symptom being more important to them than the presence or absence of the symptom. This approach aligns with the global imperative to embrace the subjective nature of person-centred outcomes and to focus on what person-centredness means to the affected population. We achieved this through adherence to the recommendations for involvement and engagement in children's palliative care research.

The study demonstrates the importance of undertaking cognitive testing to ensure tools have optimal value in research and clinical practice. The process enabled the identification and addressed potentially confusing phrases and terminologies, the variation in choice of words by developmental age, and revealed which items were not relevant to certain age-groups, for example the crying item. These insights were instrumental in informing the revisions made to

the measure, and build on the body of evidence that reveals the language used by children in the context of life-limiting illness.(35)

The C-POS has robust face and content validity properties and provides a novel and robust outcome measure for children with life-limiting and life-threatening illnesses in Uganda, country that continues to shoulder the highest burden of paediatric palliative care needs given the high prevalence of illnesses that require palliative care.(36) It is potentially a useful measure for similar settings in Africa. An outcome measure with sound psychometric properties is central to the delivery of child and family centred care. The C-POS therefore bridges a critical health systems gap in the space of paediatric palliative care in Africa.

Strengths

The development of the C-POS was underpinned by strong child, family, and health professional engagement, contributing to its acceptability among these key stakeholders. The inclusion of children with a broad range of serious illnesses enhances the tool's applicability to children commonly seen in palliative care settings. This study leveraged on learnings from the C-POS:UK team, which strengthened the use of existing evidence and informed adaptations regarding recall periods, the number of versions to work with, and age banding. Cultural variations were also noted, for instance. children in our study preferred to refer to pain as “pain” and not “hurt” and referred to activities they “enjoy” rather than those that are “fun”. Whilst the concept of anxiety was well understood by children in the UK, the phrase proved challenging for the children in Uganda.(17)

Limitations

Our study has some limitations, and whilst the original tool was developed across several countries in the region, the revised measure has only been tested in our country and will need further testing in other countries.

Conclusion

The integration of person-centred outcome measures into routine clinical care has been associated with improved communication, more systematic and comprehensive assessment of patients, and improved patient and family satisfaction with care.(8, 15) Future studies should pilot the integration of the APCA C-POS into routine care to improve outcomes of care, building on existing evidence for success.(37)

Declarations

Authorship

EN, LKF, KN, JD, EN, EN, EL, DH, ETK, JN, BM, YK, JK, AN, MM, DH, LC· RH – contributed to the concept and design of the work, acquisition, analysis and interpretation of the data. EN, LKF, KN, RH drafted the article and revised it critically for intellectual content. All authors approved the version to be published. All authors have participated in the work to take public responsibility appropriate portions of the content.

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Declaration of conflict of interest

All authors declare that they have no conflict of interest to declare.

Research ethics and patient consent

Ethical approval to conduct this study was provided by Mildmay Uganda Research and Ethics Committee (Ref-0107-202/2027).

Data management and sharing

Data can be obtained by contacting the authors

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Figures

- ☐ 😊 No pain
- ☐ 😐 Moderately
- ☐ ☹️ Overwhelming pain (interferes with daily activities)

Figure 1

example of response scale for the African C-POS