



Research in Paediatric Palliative Care: Patient Outcomes

2nd Congress on Paediatric Palliative Care: A Global Gathering

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Outcome measures (1)



- Key to improving:
 - Quality
 - Efficiency
 - Availability of PC
- Used in a variety of PC settings around the world:
 - Assess & monitor care
 - Mainly used with adults
- PROMS (Patient Reported Outcome MeasureS)

Outcome measures (2)

- Used in a variety of different ways:
 - Clinical care
 - Audit/ quality improvement
 - Research

- Clinical practice:
 - Routine care
 - Start of a patient assessment
 - Quick means of identifying and prioritising need e.g. pain management
 - To show change over time

What is an 'Outcome' in CPC?

 The change in a child's health status that can be attributed to the care provided through the 'palliative care service'

A challenge......

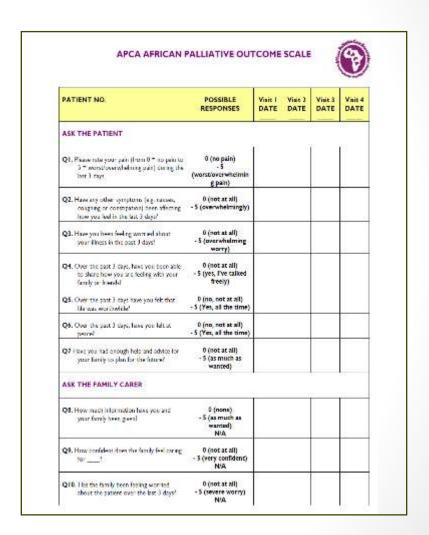


However.....

 Despite the reported need, measuring progress in the quality of PC provided to children and the outcomes of such care is challenging Measurement of outcomes in the core domains of CPC is essential in ensuring quality and efficacy of the service provided are demonstrated for both the child and their family

APCA African POS

- APCA African Palliative
 Outcome Scale was
 developed in 2005
- Mainly used for adults and not validated in children
- Issues of suitability and adaptability of the tool for use in children was discussed



C-POS Development Process....



- Commenced in 2009
- Collaborative process
- Data collection:
 - Kenya
 - South Africa
 - Uganda
 - Zimbabwe
- Others involved:
 - Malawi
 - Zambia
 - UK









What is out there?

- Literature review completed
- Looked at Paediatric Palliative care domains and tools:
 - Physical care and pain
 - Spiritual care
 - Psychosocial care
 - Quality of life
- Looked at variety of tools
- Looked at research methods in children
- Ethical issues assent vs. consent etc



Existing measures

- Physical focused mainly on the child
- Spiritual included the child and the family
- Psychosocial included the child and the family
- Measures were:
 - Uni-dimensional
 - Focused on one particular area
 - Disease specific
- Therefore there was a lack of appropriate outcome measures for use with children

Recent systematic review

- No validated outcome measures for use in CPC
- Domains of some generic measures not relevant to CPC
- Disease specific measures only relevant for given population
- Recall period and response format not considered appropriate in all measures
- Options are to adapt an existing generic measure or develop a new one.

(Coombes et al 2014)

Children's Report: Main Findings (2010)



THE STATUS OF PAEDIATRIC PALLIATIVE CARE
IN SUB-SAHARAN AFRICA - AN APPRAISAL
DR RICHARD HARDING, PROFESSOR LORRAINE SHERR,
DR RENE ALBERTYN, JULY 2010

EXECUTIVE SUMMARY





- HIV rates in children are high and rollout of ART is limited
- Very little data on childhood cancers in Africa
- The evidence base for children's palliative care has not progressed and no measurement tools exist
- Few models of children's PC discussed
- Only 5 peer-reviewed papers found

May 2009 - March 2010

Meeting of Multi-disciplinary experts from across Africa in Kampala (Kenya, Malawi, South Africa, Swaziland, Uganda, Zambia, Zimbabwe)

Development of Tool – Verbal and non-Verbal

Piloting(of(Tool(-(longitudinal(mixed2methods(approach(

Aim: Initial testing of the tool, looking at feasibility, ease of administration and utility of the tool

4 sites - Nyahururu Hospice (Kenya), Isibani Sethemba and Soweto Hospice (SA), HAU (Uganda)

Quantitative(Data(Collection(

19 verbal tools completed 21 non-verbal tools completed

Qualititative(Data(Collection(

11 Staff - semi-structured interviews re feasibility, ease of administration and utility of the tool



A pallitative care outcome measure for children in sub-Saharan Africa: early development findings in the sub-Saharan Africa: early development findings in t

(Downing et al 2012)

What should we measure?

- Need to measure outcomes that reflect the specific goals of palliative care e.g.:
 - Improving the quality of life before death
 - Controlling symptoms
 - Supporting the family (Higginson and McCarthy 1993)
- Can't measure everything as tools need to be user friendly and not over burdensome

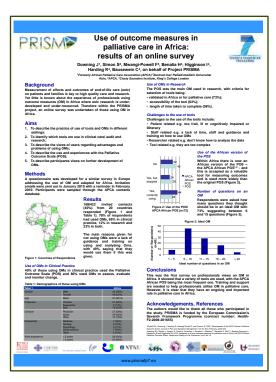


Development of draft tool

- Reviewed definition of PC for children
- Identified outcomes expected e.g.:
 - Children who are pain and symptom free
 - Children who are engaged within their own context
 - Children who have satisfactory family and sibling involvement in their life
 - Families and caregivers who feel confident with supporting the child through their illness.
- Discussed age, developmental status etc.

'Outcomes out of Africa'

- Professionals views
- 168 from 20 countries (78% used PROMS)



Challenges:

- Patient related:
 - too ill
 - illiterate
- Staff related
 - Lack of time
 - Lack of guidance
 - No training on use
- Researcher related
 - How to analyse
- Tool related
 - Too complex

Initial Tool

Non-verbal

- Children < 3 years
- Those not able to communicate verbally for whatever reason



Verbal

 Children> 3 years and able to communicate verbally

 Discussed the possibility of having a separate tool for adolescents – felt that can use the APCA African POS with minor changes

Format

<u>Section A – about the</u> <u>child</u>

- Pain
- Symptoms
- Feeding
- Sleeping
- Interacting
- Crying
- Content/ settled
- Playing
- Worry

<u>Section B – about the family/</u> <u>caregivers</u>

- Sharing of feelings
- Help and advice to plan for the future
- Information about the child's illness
- Confidence in caring for the child
- Involvement of siblings

Scales

- Verbal descriptors
- Hand scale
- Numerical rating scale
- Revised faces scale

Q2 Please rate the extent to which any other symptoms have affected your child in the past 3 days?

0 = Not at all

1 = Slightly

2 = Moderately

3 = Severely (interferes with activities of daily life)

4 = Very severely

5 = Overwhelmingly













APPENDIX 3: APCA AFRICAN CHILDREN'S POS

Version I: NON VERBAL CHILDREN

Patient Number: NV____

Respondents will be asked to respond to each question with an answer on a 0-5 scale – they may do this using either of the scales below.

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0	1	2	3	4	5

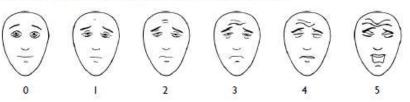
Ques	stion	POSSIBLE RESPONSES	Visit 1	Visit 2	Visit 3	Visit 4
Stud	y Reference Number:	Date				
SECT	TION A: ABOUT THE CHILD					
QI.	Please rate whether your have seen any signs of pain in your child over the last 3 days	0 (no signs of pain at all) – 5 (Signs of overwhelming pain/ the worst pain that you can imagine)				
Q2.	a) Please rate the extent to which any other symptoms (e.g. vomiting, diarrhea, skin problems etc) have affected your child over the last 3 days	0 (not at all) – 5 (Overwhelmingly)				
	b) Please tick all symptoms your child has experienced over the last three days	Cough Itching Skin problems Nausea Vomiting Sore mouth				

APCA AFRICAN CHILDREN'S POS

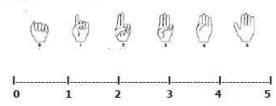
Version 2: VERBAL CHILDREN

Patient Number: V____

The Children will be asked to respond to each question by using one of the following scales – the scales will be printed on the back of the tool for ease of use.



Family respondents will be asked to respond to each question with an answer on a 0-5 scale – they may do this using either of the scales below.



Question Study Reference Number:		POSSIBLE RESPONSES	Visit I	Visit 2	Visit 3	Visit 4
		Date				
SEC	TION A: ABOUT THE CHILD					
QI.	Can you show me on a scale of 0 to 5 how much pain you have had over the last 3 days?	0 (no pain) – 5 (the worst pain you can imagine)		B-C		
Q2.	No. 2007 No. 101 275	0 (no other problems		55		4

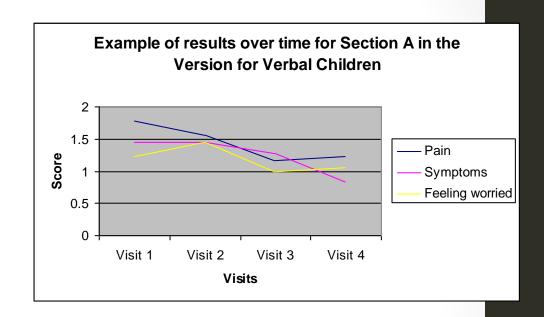
Sample of the pilot

- 4 services in 3 countries
 - Kenya,
 - South Africa
 - Uganda
- 40 patients
 - 19 verbal
 - 21 non verbal
- 5 languages
 - Kikuyu,
 - Runyoro,
 - Zulu,
 - Isinelebele
 - Sesotho

- Age range
 - Non-verbal 0.42 to 14 years
 - verbal 5 to 16 years.
- Gender
 - 58% girls
 - 42% boys
- Family size
 - 2 to 10 people.
- Setting
 - 75% rural
 - 25% urban setting

Health professionals feedback

- Enhanced communication
- Questions were appropriate
- Gave insight into child's condition and how carer's are feeling
- Made them think broadly about the care of the child



Recommendations:

- Combine two tools into one
- For pilot:
 - Completed by child if able to
 - Completed by parent/ carer
- Maintain all scales for pilot as numbers small and then review
- Change time frame to 'yesterday'
- Remove ACT class

March 2010 - Jan 2012

Meeting of Multi-disciplinary experts from across Africa in Nairobi to review results (Kenya, Malawi, South Africa, Uganda, Zambia, Zimbabwe)

Revision of Tool (Combined into one tool, changed time frame)

Piloting (of (Tool (- (longitudinal (mixed (method (approach (

Aim: To assess the utility of the tool, it's acceptability in practice, feasibility and gathering initial data on face validity

8 sites - Nyahururu Hospice and Nyanza Provincial General Hospital through Kisumu Hospice (Kenya), Isibani Sethemba and Soweto Hospice (SA), HAU, Mildmay and MPCU (Uganda), Island Hospice (Zimbabwe)

Quantitative(Data(Collection(

198 children recruited (85 Ug, 50 Ken, 44 SA and 19 Zim) 15 languages utilised 185 children completed 4 time points Time taken: T1 x=23 – T4 x=15 mins

Qualititative(Data(Collection(

In-depth and cognitive interviews
There were challenges with completing
some of these, so some interviews
completed during the validation of the
tool. Initial results used to review the
tool but full analysis during validation



Study	y Reference Number:		care	r was i	s asked t a fam r healt	rilly		Date:				
	QUESTIONS TO BE A	SKED TO THE			200.11		QUESTIONS TO BE A CARER OR NURSE IF UNABLE TO RESPON	THE CHILD IS		170000	10000	
	Question	POSSIBLE RESPONSES	Visit	Visit 2	Visit 3	Visit 4	Question	POSSIBLE RESPONSES	Visit	Visit 2	Visit 3	Visit 4
SECT	TION A: ABOUT THE CH	HLD				- Landard						
QI.	Have you had any pain since yesterday? If so can you show me how much pain you have had?	0 (no pain) – 5 (the worst pain you can imagine)					Please rate whether your have seen any signs of pain in your child sense yesterday? (If appropriate you can use the FLACC scale to rate the pain).	0 (no signs of pain at all) – 5 (Signs of overwhelming pain/ the worst pain that you can imagine)				
Q2.	a) Apart from the pain have any other problems with your body been troubling you since yesterday (e.g. being sick, going to the toilet a lot)? If so can you show me how much they have been troubling you?	0 (no other problems with my body have been troubling me) – 5 (Other problems with my body have been troubling me very much)					a) Please rate the extent to which any other symptoms (e.g. vomiting, diarrhea, skin problems etc) have affected your child since yesterday?	0 (not at all) – 5 (Overwhelmingly)				
	b) Can you tell me what	Cough					b) Please tick all	Cough				
	other problems have been troubling you? (Please tick)	Itching					symptoms your child has	Itching				
		Skin problems			1		experienced since	Skin problems				
		Nausea			1		yesterday?	Nausea				
		Vomiting						Vomiting				
		Sore mouth						Sore mouth				
		Diarrhoea						Diarrhoea				
		Constipation						POSSIBLE RESPONSES 0 (no signs of pain at all) — 5 (Signs of overwhelming pain/ the worst pain that you can imagine) 0 (not at all) — 5 (Overwhelmingly) Cough Itching Skin problems Nausea Vomiting Sore mouth				
		Breathlessness						Breathlessness			1	

Q9.	Have your questions about your sickness been answered since	0 (Have not been answered at all) – 5 (As much as I		Have your questions about your Child's illness been answerd since	0 (Have not been answered at all) – 5 (As much as I	
	yesterday?	wanted) N/A Had no questions		yesterday?	wanted) N/A Had no questions	
SECT	ION B. QUESTIONS AB	OUT FAMILY/CARER	- 11	1		- 1
Q10	Over the last 3 days have y child's illness with others v	ou been able to share how you are feeling a when you have wanted to?	about your	0 (Not at all) – 5 (Talked freely)		
QII	How much information has illness?	ve you and your family been given about you	ır child's	0 (None) – 5 (As much as wanted)		
Q12	Have you had enough help and advice for your family to plan for the future with regards to your child's illness?			0 (None) – 5 (As much as wanted)		
Q13	How confident does the family feel caring for the child?			0 (Not at all) – 5 (Very confident)		
Q14	How much have other children in the family been involved in the care of the sick child?			0 (Not at all) — 5 (Involved as much as pos N/A — the child has no sibli		
SECT	ION C. QUESTIONS TO	BE COMPLETED BY THE HEALTH	WORKING	USING THE POS DURI	NG THE PILOTING PROCESS	
Q15. P	lease record how long it too	k to complete the questionnaire during the	pilot on each	visit. (in minutes)		
Q16. P	lease record whether Section	n A was completed by the child (C), family/o	carer (F) or b	ooth (B)	7	11 11
Q17. P (O)	lease record which scale the	child used most of the time to answer the	questions in	Section A – Line (L) – Hands	(H) - Faces (F) - Other	
Q18. P	lease record which scale the	carer used most of the time to answer the	questions -	Line (L) - Hands (H) - Other	(O)	1
~			- Annahama		(-)	

Example of Findings

Quantitative

- Mean age 7.5 years
 - 58% HIV
 - 37% cancer
- High baseline scores in some areas e.g.
 Pain, symptoms, feeling unwell
- Demonstrated change over time, and each available option (0-5) scored
- Most significant change T1-T2

Qualitative

- Tool helped improve relationship between health workers and child/ carer
- Tool seen as good and encouraged child to open up
- Carers comfortable with most of the questions
- Issues raised by carers mapped with the tool

Recommendations:

- Hands and verbal scales used, faces and VAS removed (cf Blum et al 2014)
- Removed preceding questions e.g. 'Have you got pain' as if not then score 0
- Textual descriptors removed apart from the anchors (0 and 5)
- Some changes to specific questions e.g. 'feeding' instead of 'eating'
- Question on sleep removed as sleeping a lot could be good or bad
- Question on worry moved to the carer only section of the tool

Jan 2012 – Aug 2014

Review of results (by tele-conf.) by multi-disciplinary experts from across Africa (Kenya, South Africa, Uganda, Zimbabwe and the UK)

Revision of Tool (Faces scale removed, only verbal anchors for 0 and 5, N/A responses removed, since yesterday inserted, some wordings changed e.g. feeding not eating, removed sleep from the tool, moved question on worry from the child to the carer)

Validation(of(Tool(-(longitudinal(mixed(method(approach(

Aim: To assess the validity of the tool, establishing face, content and construct validity, reliability and acceptability of the APCA African C-POS 3 sites - Nyanza Provincial General Hospital through Kisumu Hospice (Kenya), The Red Cross Children's Hospital (SA), Mildmay (Uganda) – 6 translations used Swahili, Luo, Runyakitara, Lugana, Afrikaans and isiXhose

Quantitative(Data(Collection(

302 children recruited (101 Ug, 99 Ken, 102 SA) and 299 family carers Completed C-POS and PedsQL for construct validity Time taken: T1 med=15,T4 med=5 mins

Qualititative(Data(Collection(

In-depth and cognitive interviews
61 interviews from 6 sites
Cognitive interviews: 12 staff, 16 carers,
6 children
In-depth interviews: 11 carers, 16
children

September 2014

- Reviewed data
- Found it to be valid, reliable and acceptable when completed by the child and proxy
- Finalised tool
- Writing paper for publication
- Dissemination



Challenges - the tool

- Choosing which domains to cover
- Concepts may mean different things to different people
- Multiple languages
- No similar tool to compare it with (construct validity)
- Which scale to use
- ?carers as proxy for children

Challenges - the process

- time taken to get ethical approval
- Change in key research team personnel
- Key people at the sites not being available
- Some sites not familiar with the POS and new to research
- Conducting research across countries
- Donor requirements
- It always takes longer than you think it will!

Recommendations

- There is a role for PROMS in children's PC
- The use of the APCA C-POS to be rolled out in different sites/ different countries.
- Project to develop a similar outcome scale for use in CPC in the UK.
- More work needed on the use of carers as proxies for children
- The use of PROMS is an important step in evaluating the outcomes of the care that we provide and ultimately therefore in improving quality of care.

Save the dates....





Medicine and Compassion: Tool for the Task... Or Dangerous Distraction?

7TH CARDIFF INTERNATIONAL CONFERENCE 2015
PAEDIATRIC PALLIATIVE CARE

8th - 10th July 2015





Thank You



I would like to acknowledge all those involved in the different aspects of this work.