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International

Better care at the end of life

WHO Collaborating Centre
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Rehabilitation



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Quality of life- what matters to people living with HIV? Findings from an international programme

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Summary

- What do we know matters from global primary studies:
 - Qualitative
 - Quantitative
- What are the risks of ignoring patient-report problems?
- Towards person-centred care
- The importance of outcome measurement
- Findings from clinical trials

Qualitative/ open ended data:

“Positive futures”: what is needed to achieve quality of life?

- N=347 UK gay men living with HIV
- Key themes to open ended question:
 - Better clinical care/medications
 - “More understanding from the HIV doctors. i.e. side effects and mental illness”*
 - “Improved clinical services/mental health”*
 - Maintain general health
 - “More energy!” “Illness=worse depression” “positive outlook”*
 - Personal skills
 - “I need to rebuild my confidence and self esteem” “need to find a way mental structure to move forward in every area of life”*

Harding & Molloy AIDS Care 2007

ACCESS care

- N=40 LGB and/or T people across the UK with advanced illness
- Tom 44, gay man with HIV & COPD
 - *"With the COPD I've felt very, very excluded... they don't get patients like me... So when I've had pulmonary rehab, it's me and a class of eighty year old women... I can't be the only 44 year old out there with bad lungs."*
 - *"The main problem is have is **breathlessness**...which leads to **mobility** issues.....to **social isolation** and to generally sort of **hiding away from everyone**"*
 - *"Because of my **various conditions** I have to **juggle 7 or 8 health care providers**. I have **no idea**"*

- Edward, 64, gay man living with HIV and prostate cancer
 - *“Not knowing what's out there...**how do I know what question to ask? ...That's the difficulty that I have...if somebody came up to and said, "Right, OK, XYZ that's what you've got in front of you"...Then I can start asking the right questions...and I finish up spending an hour of somebody's time just trying to work out what's good for me. **Nobody's bothered to sit down and really talk about what's going on and what's out there what sort of support groups are out there. Umm, I've had to sort of muddle my way through, just to find out things.**”***

- Joe 52, gay man with HIV and COPD
 - “I invariably go into **A&E** [hospital X], we’re on 1st name terms...they **clerk me in easily. I’ve had excellent care.** But if I go to [hospital Y]...not a nice place to end up...they don’t have a back story there. It’s **hard to go through 20 or 30 years of history when you’re breathless.** Before they were happy to drive me to hospital X 45 minutes away, now they don’t think I’ll make it so they take me 15 minutes away to hospital Y.”
 - “The other main symptom I’ve had is **falls.** I have **Cushing syndrome from the steroids** and terrible **pain and leg weakness. I get stuck in the bath**”
 - “I think that's what put me at the **suicide risk** in the first place. **Severe worrying**”

PEPFAR data

- 83 patients, 47 caregivers, 59 staff, 12 sites in Kenya & Uganda

– *“And my **chest is painful and uncomfortable**; I am coughing and producing very black/dark saliva and thus I am wondering why.I have painful joints and especially when I am sleeping.*

Interviewer: So you have painful joints?

Respondent: Yes, whenever I lie down, it becomes difficult to rise up.” P3 Fac E

- *“My whole body hurts and I spend a lot of time in bed; I have no energy and I am not able to get out of bed” P6 Fac E*
- *“Sometimes she has this severe pain in her right leg and some times she applies medicines and it stops but it is recurrent. Maybe after a month or two weeks or even after a week. Like now she is experiencing the pain and that’s why she is not able to walk up here with me and that is why I am here to collect her drugs from this clinic.” C1 Fac L*

- *“Yes, like the ARVs at times cause me stomach pains and pains in the legs and at times severe headache and rotational dizziness and I feel as if I lose balance and focus.” P3 Fac L*

“She has been falling sick often, time and again she is down with malaria, fever, diarrhoea and general body pain and these days she gets severe pain in the bones and this pain has limited her from doing any other work. There is a lot of pain in the joints, she feels these are the problems she has being HIV positive client and these never used to have them before.”

C4 Fac G

BMC Palliative Care 2013

Quant studies: EURQoI

Quality of Life EUROQoL 5-D n=778 UK outpatients

	N	%
Quality of life A – Mobility		
1: I have no problems walking about	538	71.9
2: I have some problems walking about	207	27.7
3: I am confined to bed	3	0.4
Quality of life B – Self-care		
1: I have no problems with self-care	608	81.3
2: I have some problems with self care	136	18.2
3: I am unable to wash or dress myself	4	0.5
Quality of life C – Usual activities		
1: I have no problems performing my usual activities	464	62.5
2: I have some problems with performing usual activities	257	34.6
3: I am unable to perform my usual activities	21	2.8

Results 3: Quality of Life EUROQoL 5-D

	N	%
Quality of Life D- Pain/discomfort		
1: I have no pain or discomfort	413	55.7
2: I have moderate pain or discomfort	287	38.7
3: I have extreme pain or discomfort	42	5.7
Quality of Life E- Anxiety/ Depression		
1: I am not anxious or depressed	312	41.9
2: I am moderately anxious or depressed	355	47.7
3: I am extremely anxious or depressed	78	10.5

EUROQoI VAS n=778

Scale 0-100	N	%
	Quality of life F – General health	
0-25	21	2.8
26-50	181	24.4
51-75	239	32.2
76-100	300	40.5

EUROQoL:

Multivariable analysis, what is associated with VAS score?

- EUROQOL dimensions:
 - Mobility (95% CI) -4.25 (-8.25, -.24) for some problems compared to no problems, $p = .038^*$,
 - Usual activities B (95% CI) -6.97 (-10.54, 3.41) and -12.24 (-20.85, -3.63) for some problems and unable to perform compared to no problems, $p < 0.001^{***}$
 - Pain/discomfort B (95% CI) -4.18 (-7.24, -1.11) and -10.32 (-16.67, 3.96) for moderate and extreme compared to no problems, $p < 0.001^{***}$
 - Anxiety/depression B (95% CI) -8.08 (-10.90, -5.26) and -13.16 (-18.32, -8.01) for moderate and extreme compared to no problems, $p < 0.001^{***}$
- Treatment optimism
 - B (95% CI) 4.83 (1.77, 7.89) for optimistic compared to not optimistic, $p = .008^{**}$
- Sexual partner
 - having a sexual partner B (95% CI) 3.58 (.42, 6.74) $p = .035^*$
- **NOT SIG**
 - Self care, employment, Education, UK born, age, relationship, gender/sexuality, ethnicity, sexual risk, STI, disclosure, ART, CD4, viral load
- Variance 45% explained

AIDS Care 2012

Symptom studies

UK 10 most prevalent (physical) n=778

Symptom	7 day prev	Level of distress (% whole sample)				
		<i>Not at all</i>	<i>Little bit</i>	<i>Some-what</i>	<i>Quite a bit</i>	<i>Very much</i>
Lack energy	70.8%	10.8%	19.8%	12.3%	12.1%	10.8%
Drowsy/ tired	67.5%	10.7%	19.8%	9.8%	12.3%	10%
Difficulty sleeping	61.8%	13.5%	10.9%	9.5%	12.1%	10.9%
Difficulty concentrating	60.7%	16.6%	15.2%	10.3%	9.1%	5.5%
Diarrhoea	53.6%	17.6%	12.6%	7.5%	7.5%	5.4%
Sexual activity	53.5%	15.7%	8.1%	6.6%	7.1%	12.2%
Pain	53.2%	18.0%	12.0%	5.9%	8.6%	5.4%

UK 10 most prevalent (psychological)

	7 day period prev	Intensity			
		<i>Rarely</i>	<i>Occasionally</i>	<i>Frequently</i>	<i>Constantly</i>
Worried	69.9%	8.4%	25.4%	21.5%	9.1%
Sad	66.3%	11.8%	26.9%	16.7%	6.2%
Feeling irritable	56.6%	10.4%	22.4%	16.3%	4.2%

Harding et al BMJ STI 2010

Adult HIV symptom datasets

London
n=778
outpatients

Argentina
n=200
outpatients

Kenya
n=378
outpatients

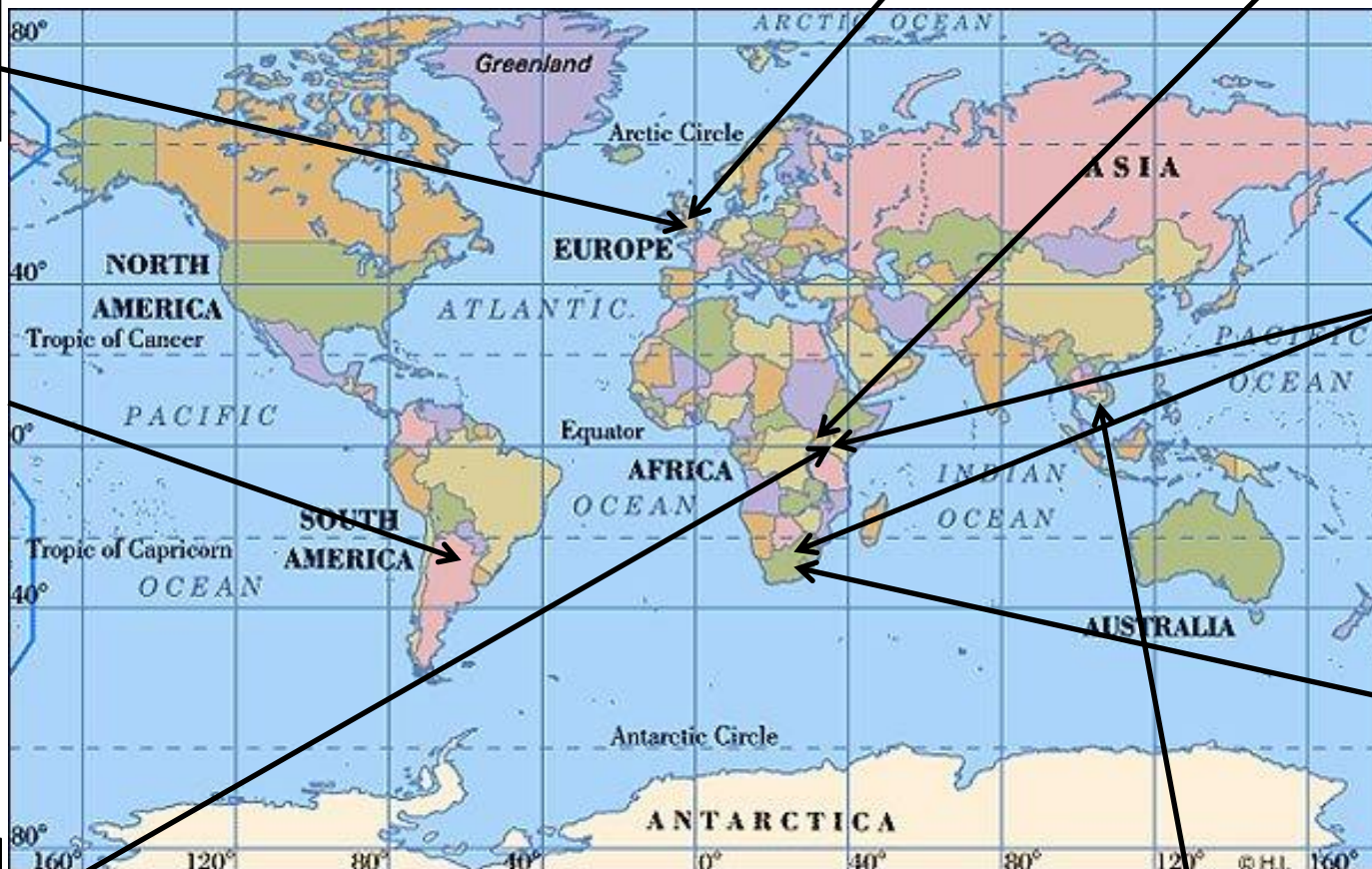
UK
n= 347
Gay men

Uganda
n= 200
newly
diagnosed

5 sites
Uganda
& South
Africa
n= 224
advanced
pts

SOWETO
n= 385
ART
outpatients

VIETNAM n=1134
outpatients



Key messages

- Pain & symptom burden assoc with:
 - Risk *Harding et al BMJ STI 2010*
 - Poor adherence *Harding et al AIDS & Behavior 2012*
 - Viral rebound *Lampe et al JAIDS 2010*
 - Poorer QoL *Harding et al AIDS Care 2011*
 - Suicidal ideation 31% *Sherr et al AIDS 2008*
 - ART Discontinuation/change *Sherr et al HIV Med 2011*
- Older gay men stigma accounts 39% QoL variance *Slater et al J Assoc Nurses AIDS Care 2014*
- Prayer & meditation used to improve subjective wellbeing *Ridge 2008 Sociology Health & Illness*
- ART does improves quality of life (Bucciardini 2014)
- QoL “critical challenge” to HIV medicine *Buscher JAMA 2010*
- Few intervention studies in person-centered care *Harding Lancet Infect Dis 2012*

PEPFAR data: POS & MOS-HIV

In context: 90x90x90 by year 2020

- By 2020 in Africa alone that's 15,000,000!
- N=1336 n=102-125 per facility (12 sites 2 countries)
- 68.3% female, mean age 34.8 years
- % sample with CD4 > 350 range 28.0-53.5%
- On ART 8.3-91.6%



Results: POS scores

Item	% low (0-1 score)	% moderate (2-3 score)	% severe (4-5%)
Pain	42.1	48.2	9.7
Symptoms	41.3	36.7	4.6
Worry	58.7	22.9	17.4
Sharing feelings	21.1	31.2	47.7
Life worthwhile	80.7	15.6	3.7
At peace	60.6	28.4	11.0
Help/advice	40.4	22.9	36.7

Results: quality of life scores

- Among the 1,337 participants,
 - multivariable analysis using GEE to adjust for facility effect
 - mental health subscale of MOS-HIV lower for people with limited functional status (B=-5.27, 95% CI -5.99, 1.-4.56 p<0.001)
 - physical health subscale lower for those with limited functional status (B=-8.58, 95% CI -9.46 to -7.70, p<0.001)
 - Multidimensional problems more burdensome for people with limited functional status (B=-2.06, 95% CI -2.46 to -1.66, p<0.001)

– BMC Infect Dis 2014

Newly diagnosed: longitudinal 4 months

- Secondary analysis, n=438 adults within 2 weeks
- 234 (53.4%) initiated ART during the study period
- Adjusted for demographic and clinical variables
 - improvement over time was found for MOS-HIV physical health (from 46.3 [95% CI 45.1-47.3], to 53.7 [95% CI 52.8-54.6], $p < 0.001$),

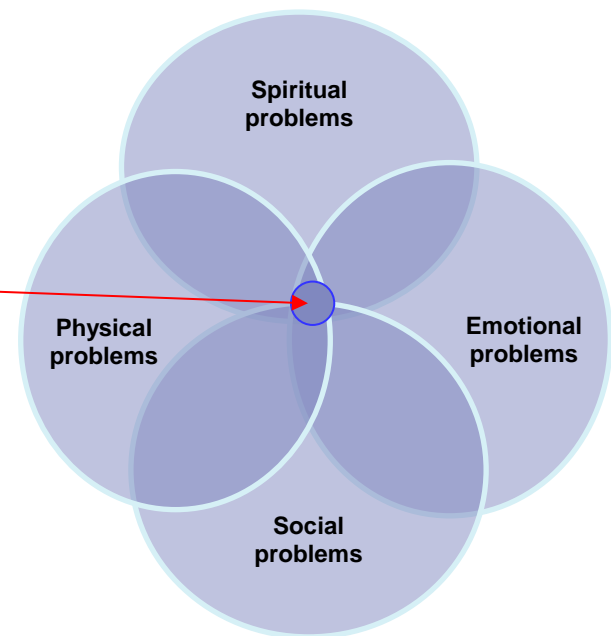
- Limited physical function at baseline was associated with:
 - worsening PHS (OR=-8.69, 95% CI=-10.18, -7.21, $p<0.001$)
 - worsening MHS (OR=-4.93, 95% CI=-6.09, -3.76, $p<0.001$)
 - worsening physical/psychological subscale (OR=4.29, 95% CI=2.94-6.26, $p<0.001$)
 - Worsening existential subscale (OR=2.92, 95% CI=1.89-4.50, $p<0.001$).
- ART initiation improved mental health but not psychical health

Towards person-centred care

Conceptual approaches: 'health' & 'quality of life'


- *“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”* WHO 1948
- *“HRQOL is an assessment of how the individual's well-being may be affected over time by a disease, disability or disorder”* CDC
- Patient-oriented care:

*“From the life of the virus
to the life of the host”*



Programme of African POS measurement

Harding et al. *Health and Quality of Life Outcomes* 2010, **8**:10
<http://www.hqo.com/content/8/1/10>



RESEARCH **Open Access**

Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale

Richard Harding^{1*}, Lucy Selman¹, Godfrey Aguppo², Natalya Dina³, Julia Downing¹, Liz Gwyther³, Thandi Mashao⁴, Keleto Mmoleki⁵, Tony Moll⁶, Lydia Mpanga Sebujira⁷, Barbara Panjaitov⁸, Irene J Higginson¹

Abstract
Background: Despite the burden of progressive incurable disease in Africa, there is almost no evidence on patient care or outcomes. A primary reason has been the lack of appropriate locally-validated outcome tools. This study aimed to validate a multidimensional scale (the APCA African Palliative Outcome Scale) in a multi-centred international study.
Methods: Validation was conducted across 5 African services and in 3 phases: Phase 1. Face validity: content analysis of qualitative interviews and cognitive interviewing of POS; Phase 2. Construct validity: correlation of POS with Messoula-Vita Quality of Life Index (Spearman's rank test); Phase 3. Internal consistency (Cronbach's alpha calculated twice using 2 datasets), test-retest reliability (Intraclass correlation coefficients calculated for 2 time points) and time to complete (calculated twice using 2 datasets).
Results: The validation involved 682 patients and 437 family carers, interviewed in 8 different languages. Phase 1. Qualitative interviews (N = 30 patients; N = 38 carers) showed POS items mapped well onto identified needs; cognitive interviews (N = 73 patients; N = 29 carers) demonstrated good interpretation; Phase 2. POS-MVQoL Spearman's rank correlations were low-moderate as expected (N = 263); Phase 3. (N = 307, 2nd assessment mean 21.2 hours after first, SD 7.2) Cronbach's Alpha was 0.6 on both datasets, indicating expected moderate internal consistency; test-retest found high intra-class correlation coefficients for all items (0.78-0.89); median time to complete 7 mins, reducing to 5 mins at second visit.
Conclusions: The APCA African POS has sound psychometric properties, is well comprehended and brief to use. Application of this tool offers the opportunity to at least address the omissions of palliative care research in Africa.

Background
 The lack of clinical and research activity to enhance care of the dying among those HIV-infected is a global challenge. Despite two million deaths during 2007, with emerging international data reporting high mortality even as access to therapy increases, very little scientific attention is paid to improving the experience of death and dying [1].
 The burden of progressive, life-limiting disease in sub-Saharan Africa is reflected in the epidemiology of HIV

[2,3] and cancer [4]. In sub-Saharan Africa during 2007 there were 22.5 million people living with HIV infection; 1.7 million adults and children became infected with HIV; and 1.6 million died of AIDS [1]. Based on GLOBOCAN 2002 cancer rates and UN population predictions, there were an estimated 7.6 million new cancer cases and 6 million deaths from cancer in Africa in 2007 [5], and malignancies are a common presentation of HIV progression. The burden of other progressive non-malignant diseases is unknown.
 Significant advances have been achieved in African palliative care provision to manage the highly prevalent and burdensome problems experienced by those with incurable terminal disease. However, there is very little

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Journal of Pain and Symptom Management 229

deaths in Africa³ and that by 2020, new cancer cases will be in the developed world.⁴ For the overwhelming majority of those who currently endure these and other severe, life-limiting illnesses, access to culturally appropriate holistic palliative care (that is effective pain management) is at best limited, and at worst nonexistent.⁵ Addition to extending the coverage of palliative care services across the continent, the sub-Saharan African Palliative Care Association (APCA) was established to ensure that a minimum optimal level of quality that meets their resource-constrained optimal environment. Progress achieved in many of care provided apart of a continuum of palliative care, however, must be identified, and inform routine service-level practice to be sustainable. Despite the need among care providers, 'measuring' is in the quality of palliative care provision in Africa is problematic: in the absence of validated outcome instruments,⁶ relying on death of empirical evidence is unclear to palliative care but indeed is symptomatic of a wider problem: the 'modernity' of African health research.⁷ Consequently this study sought to develop a simple and brief multidimensional outcome measure for palliative care: the APCA African Palliative Outcome Scale (POS) using patient-level indicators that could be used in routine clinical practice.

Methods
 An expert panel review was conducted in WHO's definition of palliative care.⁸ An expert panel represented six countries of which were African, and was multinational in nature, comprised of clinical, academic and advocating professionals. The key issues of palliative care were identified for content panel and symptom relief, across

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and current use. Participants addressed issues of appraising current practice and priorities for the development and application of a valid, acceptable and appropriate outcome measure within the African context. None of the 32 multidisciplinary palliative care participants were currently using a multidimensional palliative care scale. Current practice (using outcomes related on the use of bed scales, longhand note taking, and use and recall of previous health status, indications for future measures included items that take account of the family/disease, the difference between HIV or patient trajectories, and the paediatric advanced disease in South Africa. Resources should be allocated to staff to familiarise them with measure use, structure to be able to utilize outcome of ensuring acceptability and appropriate patients and families in terms of identification and identifying mechanisms to the data collection. Recommendations have been given in the data, addressing: (i) service enablement and transitional research; (ii) in within South Africa; (iii) development equally applicable to HIV and cancer but tools for children; (iv) inclusion of families; and (v) support for staff to implement. The design of multidimensional outcomes using this guidance is timely to inform current practice, and to guide and service development. **KEYWORDS:** HIV; cancer; outcome measure; sub-Saharan Africa, South Africa

adults and children living with HIV/AIDS in sub-Saharan Africa, with 2.4 million AIDS-related deaths and 3.5 mil-

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 (page number not for citation purposes)

bioRxiv

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Sub-Saharan Africa: a survey of palliative care

Richard Harding¹, Joseph F O'Neill¹

Abstract
 The purpose of this study was to assess the current state of palliative care in sub-Saharan Africa. The study was conducted in 14 countries with a mean population of 30 million. The study found that palliative care is not widely available in sub-Saharan Africa. The study also found that there is a need for more research into palliative care in sub-Saharan Africa. The study was conducted in 14 countries with a mean population of 30 million. The study found that palliative care is not widely available in sub-Saharan Africa. The study also found that there is a need for more research into palliative care in sub-Saharan Africa.

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Review

By HIV and cancer care in sub-Saharan Africa, and how to develop such services, that carry resource implications. Home capacity and the resources and clinical trials must be primary concerns. Simple solutions to community needs and capacity, throughout the disease course (including end-of-life care) are needed. The review discusses the current state of palliative care in sub-Saharan Africa, and how to develop such services, that carry resource implications. Home capacity and the resources and clinical trials must be primary concerns. Simple solutions to community needs and capacity, throughout the disease course (including end-of-life care) are needed. The review discusses the current state of palliative care in sub-Saharan Africa, and how to develop such services, that carry resource implications.

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of palliative care and evaluation findings. During 2003, funders, non-governmental organisations, associations, and practitioners involved in

end of life, advanced disease, sustainability, and coverage together with the needs of all named sub-Saharan African countries and Africa.

The APCA African POS

- Only 10 items (7 pt, 3 family)
- Each item scores 0-5
- Can take as little as 3 minutes to complete
- Translated into Afrikaans, SeSotho, SeTswana, isiXhosa and two isiZulu dialects (Gauteng and Natal), Luganda, Runyankole, Runyoro, Kenyan Swahili, Tanzanian Swahili, Dholuo **Mauritania**
- South → North learning
 - “at peace” item

Evolution of HIV PROM use in Africa

1. Embedded into routine practice, audit, training, management, resource allocation & research

E.g. CASIPO

2. Devt & validation of first PROM for children:

South→North learning

3. Sensitivity & specificity of scoring systems for low literacy

Methodological devt for communication

Commentary

Feedback from African palliative care practitioners on the use of the APCA POS

Kath Delleppi, Julia Downing

An appraisal of the status of palliative care in Africa conducted on behalf of the African Palliative Care Association (APCA) in 2004 found that, for the overwhelming majority of African palliative care, HIV/AIDS, and other life-threatening diseases, access to culturally appropriate holistic palliative care that included effective pain management was to be limited and, at worst, nonexistent¹. Harding and Higginson² (2006). Not surprisingly, the need for increasing the accessibility and coverage of palliative care without compromising on quality was identified as a primary concern among palliative care practitioners in the region (Harding et al., 2010). However, measuring the quality of care provided was problematic without rigorously validated outcome measures that reflected the disease profile on the continent and were suitable for use within the resource-constrained and culturally different African context. The Palliative Outcome Scale (POS) measures patient physical symptoms, their psychological, emotional, and spiritual needs, and the presence of information and support at the end of life (Haens and Higginson, 1999; <http://www.pain.org>), but although it has been widely used for cancer patients in the developed world it had not been validated for African settings.

The African Palliative Care Association (APCA) African Palliative Care Outcome Scale (APCA POS) is a brief multidimensional outcome measure that was patient and family indicators specifically developed and validated for use in the African context (Pruett et al., 2007; Harding et al., 2010). This tool was developed under the auspices of the APCA, a multi-professional expert group that included appropriately experienced African and international palliative care practitioners. It was informed by the significant adapted from the original POS (Ho, 2002). The group deemed it important that a palliative care measurement tool for use in Africa be locally validated, appropriate for both people with cancer and

people with HIV, and relevant across the disease trajectory (Selman and Harding, 2010). Although the scientific principle underpinning palliative care outcome measurement are translatable, it is essential that outcome measures reflect the prevailing illnesses and culture (Harding et al., 2007). Owing to the varying levels of interest and family literacy in Africa, the APCA POS can be completed either by the patient themselves or by a member of staff asking the questions. All answers are scored using Likert scales from 0 to 5, with numerical and descriptive labels. The items address physical and psychological symptoms, spiritual and emotional concerns, and psychosocial needs. The APCA POS measures key domains of palliative care, which include pain and symptom relief, emotional and spiritual support and grief counselling, support for family caregivers, and advanced care planning. Unlike with the original POS, there is only one version for both the patient and the family care, with the five core questions aimed at the patient and the remaining three at the carer (Pruett et al., 2007; Harding et al., 2010). It was necessary for the tool to be simple and easy to use so that progress achieved in the quality of care provided could form part of a continuous improvement strategy that could be used to inform daily practice (Harding et al., 2008).

Workshop on using the APCA POS to improve patient outcomes
A workshop conducted by the authors of this article took place during the recent APCA and Hospice Palliative Care Association of South Africa conference held in Johannesburg on 17-20 September 2013. The 70 conference delegates who participated in the workshop came from a number of African countries, including Zimbabwe, Uganda, Kenya, South Africa, Rwanda, Mozambique, Nigeria, Tanzania, Malawi, Namibia, Ghana, Cameroon, Cambodia, and the French Guiana. They included clinicians currently providing

National viewpoint

A palliative care outcome measure for children in sub-Saharan Africa: early development findings

Julia Downing, Madeline Ojig, Richard A Powell, Zipporah Ali, Sean Marston, Michelle Meiring, Annelise Sonogob, Stephen Williams, Faith Mwangi-Powell and Richard Harding discuss the initial phases of creating a palliative care outcome scale for children in sub-Saharan Africa

There is a need for palliative care for children in sub-Saharan Africa as a significant proportion of the population live with a mortality rate of 14.5% for children under five years of age.¹ In addition, 3.1 million children in sub-Saharan Africa are

living with HIV,² and 84% of the 366,000 children diagnosed annually with cancer live in the developing world, many of them in sub-Saharan Africa.³

Children's palliative care is a relatively new discipline in the continent, and continuing effort is required to expand access to quality palliative care for children. The measurement of the core domains of palliative care is essential to ensuring that the quality and efficacy of palliative care are demonstrated at both the patient level and the family outcome level.

While the development of the African Palliative Care Association (APCA) African POS of the African Palliative Care Association (APCA)⁴ was an important advance in measuring outcomes, evidence from clinical practice and a report on the status of children's palliative care in sub-Saharan Africa have highlighted the lack of a comparably validated paediatric measurement tool. Consequently, the authors sought to develop and validate a simple and brief multidimensional outcome measure for children's palliative care in the APCA African Children's POS (C-POS) that could be used in routine clinical practice as well as in research and across different diagnoses. The development of the tool followed a similar process to that used to develop the APCA African POS and the original POS, including piloting and two validation⁵.

In this article, the authors describe the initial development and piloting of the APCA African C-POS.

Key points

- In sub-Saharan Africa, the high prevalence of life-limiting illness among children necessitates a public health approach to palliative care provision to ensure quality and efficacy are demonstrated. Measurement of the core domains of palliative care is essential.
- While the development of the African Palliative Care Association (APCA) African POS of the African Palliative Care Association (APCA)⁴ was an important advance in measuring patient and family outcomes, a comparably validated paediatric tool was lacking. The authors of this article thus sought to develop such a tool – the APCA African Children's POS (C-POS).
- Key palliative care domains were identified, against which potential measurement indicators were developed, including pain, symptoms, distress, quality of life, communication and family support. Two versions of the APCA African C-POS were developed for non-validated verbal children and piloted across four sites.
- High baseline needs were evident in terms of pain, symptoms and worry about the child's illness, with significant improvements seen in these domains. Healthcare professionals felt the tool enhanced communication and increased insight into children's conditions.
- The results of the pilot study suggest that the APCA African C-POS is a useful tool to measure outcomes and to respond to change. Amendments were made to the tool following an expert review of the findings, and further validation is under way.

Hoare et al. *Health and Quality of Life Outcomes* 2014, 14:118
<http://dx.doi.org/10.1186/s12916-014-0118-1>



RESEARCH Open Access

Self-report measurement of pain & symptoms in palliative care patients: a comparison of verbal, visual and hand scoring methods used in Sub-Saharan Africa

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Abstract

Background: Despite a high incidence of life-limiting disease, there is a deficit of palliative care outcome evidence in sub-Saharan Africa. The need for end-of-life care calls for appropriate measurement tools. The objective is to compare four approaches to self-report pain and symptom measurement among African palliative care patients completing the African Palliative Care Association African Palliative Outcome Scale (APCA POS).

Methods: Patients were recruited from five services (4 in South Africa and 1 in Uganda) research nurses cross-sectionally administered POS pain and symptom items in local languages. Each question was scored from 0 to 5 using a method: verbal asking, demonstrating the score using the hand (H), selecting a face on a visual scale (V) and indicating a point on the Jemton visual scale (J). V and J scores were correlated with verbal scores using Spearman's rank and weighted kappa. A Receiver Operating Characteristic (ROC) analysis was performed.

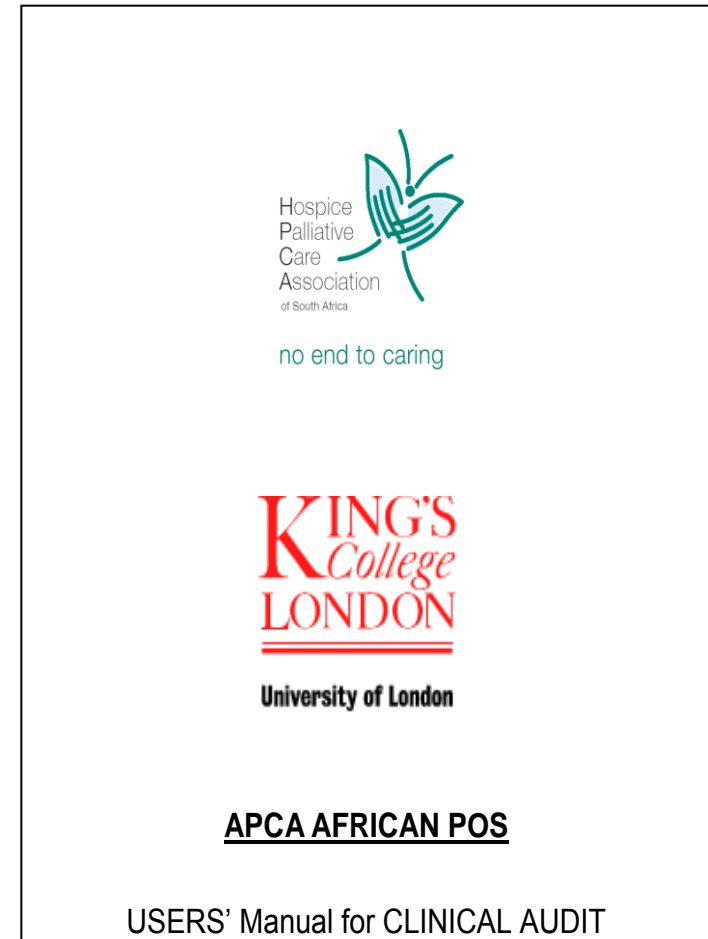
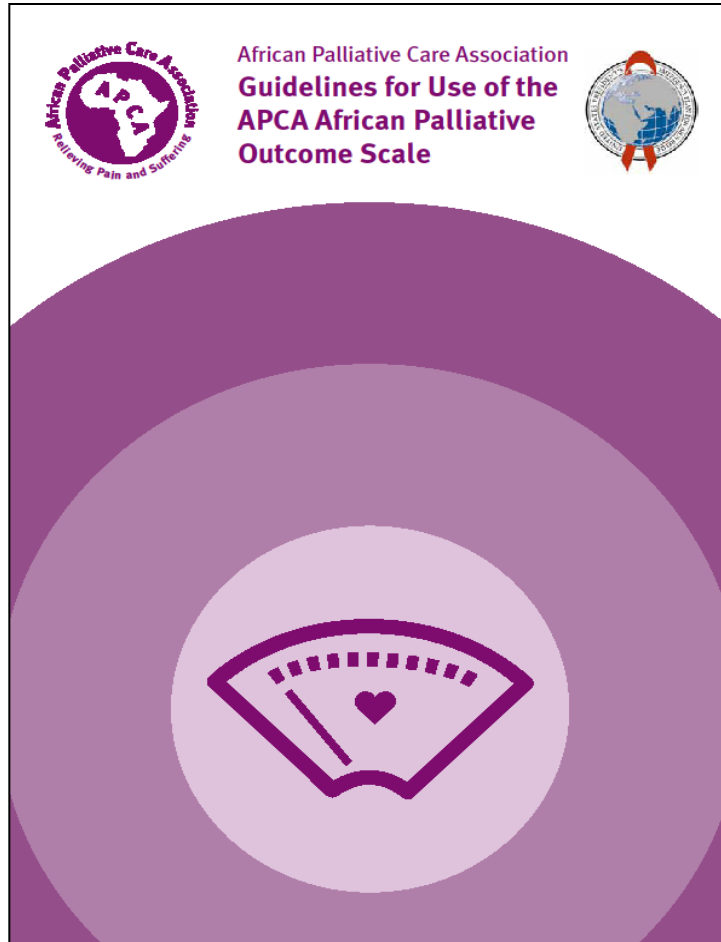
Results: 103 patients participated (mean age 61.5 years, 50% female). 71% used the V position and 30% had scores 40-50 based in rural areas. Spearman's correlation for pain scores were in US: V, F, 0.63; V, J, 0.78; V, H, 0.68 and for symptoms: H, 0.68; V, 0.68; J, 0.72. There was lower agreement between verbal and both hand and face scoring methods in the Ugandan sample. Compared to the verbal scale the accuracy of predicting high pain/symptoms was 81% for V, 65% for H, 60% for J.

Conclusions: Hands and face scoring methods correlated highly with verbal scoring. The Jemton method had only moderate weighted kappa. POS scores can be reliably measured using hand or face scales.

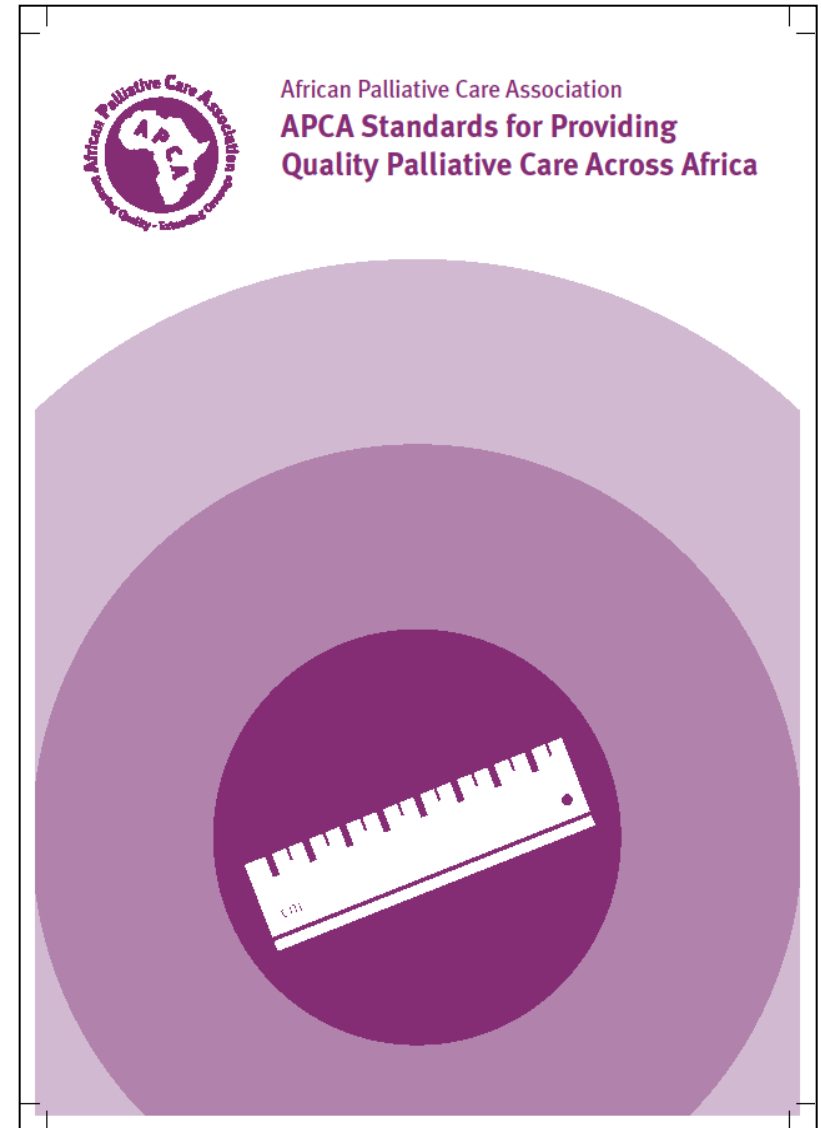
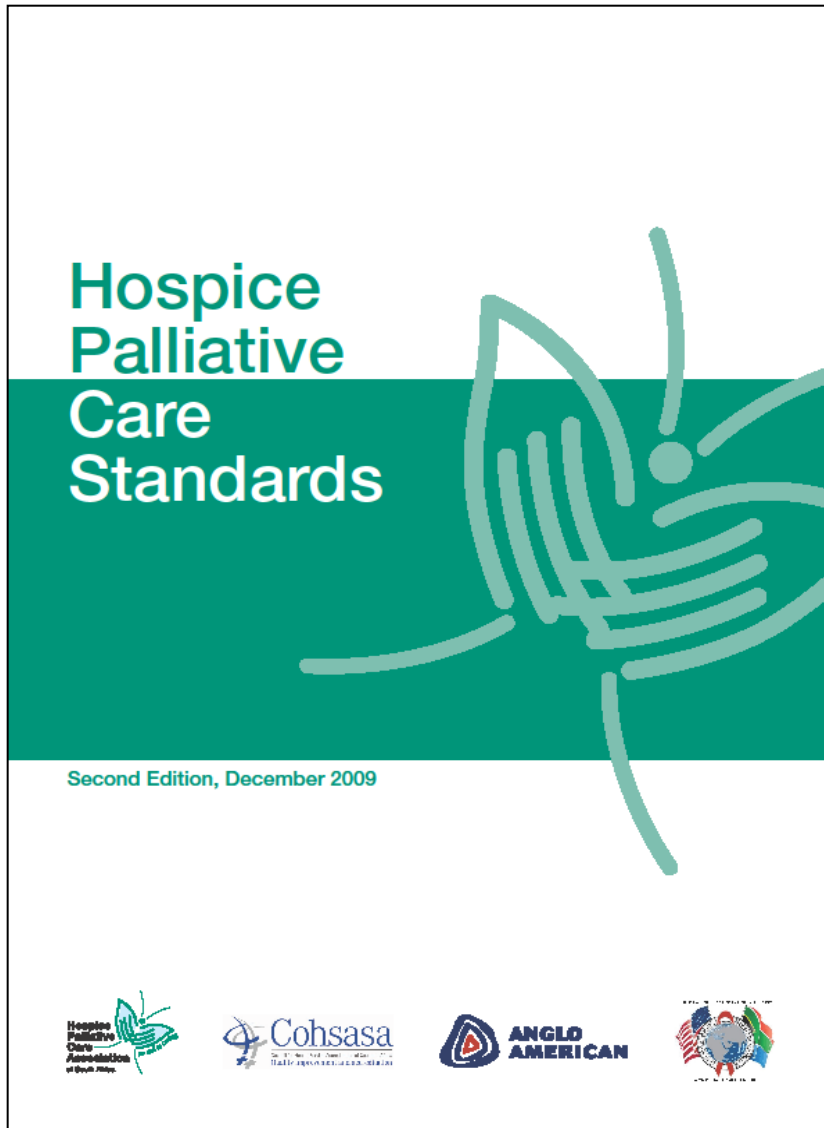
Keywords: Outcomes, Africa, Assessment, Pain, Symptoms

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African guidance on outcome measurement



Measurement as a standard



Views from the field

72 delegates, 16 countries

*“measuring the **quality of care** provided was problematic without rigorously validated outcome measures that.....were suitable for use within the resource-constrained and culturally different African context.”*

Commentary

Feedback from African palliative care practitioners on the use of the APCA POS

Kath DeFilippi, Julia Downing

An appraisal of the status of palliative care in Africa conducted on behalf of the Diana Princess of Wales Memorial Fund in 2004 found that, for the overwhelming majority of Africans enduring cancer, HIV/AIDS, and other life-limiting diseases, access to culturally appropriate holistic palliative care that included effective pain management was 'at best limited and at worst nonexistent' (Harding and Higginson, 2004). Not surprisingly, the need for increasing the accessibility and coverage of palliative care without compromising on quality was identified as a primary concern among palliative care practitioners in the region (Harding et al, 2010). However, measuring the quality of care provided was problematic without rigorously validated outcome measures that reflected the disease profile on the continent and were suitable for use within the resource-constrained and culturally different African context. The Palliative Outcome Scale (POS) measures patients' physical symptoms, their psychological, emotional, and spiritual needs, and the provision of information and support at the end of life (Hearn and Higginson, 1999; <http://pos-pal.org/>), but although it has been widely used for cancer patients in the developed world it had not been validated for the African setting.

The African Palliative Care Association (APCA) African Palliative care Outcome Scale (APCA POS) is a brief multidimensional outcome measure that uses patient- and family-level indicators specifically developed and validated for use in the African context (Powell et al, 2007; Harding et al, 2010). This tool was developed under the auspices of the APCA by a multi-professional expert group that included appropriately experienced African and international palliative care practitioners. It was informed by but significantly adapted from the original POS (Dix, 2012). The group deemed it important that a palliative care measurement tool for use in Africa be locally validated, appropriate for both people with cancer and

people with HIV, and relevant across the disease trajectory (Selman and Harding, 2010). Although the scientific principles underpinning palliative care outcome measurement are transferable, it is essential that outcome measures reflect the prevailing illnesses and culture (Harding et al, 2007). Owing to the varying levels of patient and family literacy in Africa, the APCA POS can be completed either by the patient themselves or by a member of staff asking the questions. All answers are scored using Likert scales from 0 to 5, with numerical and descriptive labels. The items address physical and psychological symptoms, spiritual and emotional concerns, and psychosocial needs. The APCA POS measures the key domains of palliative care, which include pain and symptom relief, emotional and spiritual support and grief counselling, support for family caregivers, and advanced care planning. Unlike with the original POS, there is only one version for both the patient and the family carer, with the first seven questions aimed at the patient and the remaining three at the carer (Powell et al, 2007; Harding et al, 2010). It was necessary for the tool to be simple and easy to use so that progress achieved in the quality of care provided could form part of a continuous improvement strategy that could be used to inform daily practice (Harding et al, 2008).

Workshop on using the APCA POS to improve patient outcomes

A workshop co-chaired by the authors of this article took place during the recent APCA and Hospice Palliative Care Association of South Africa conference held in Johannesburg on 17–20 September 2013. The 72 conference delegates who participated in the workshop came from a number of African countries, including Zimbabwe, Uganda, Kenya, South Africa, Rwanda, Botswana, Swaziland, Nigeria, Tanzania, Malawi, Namibia, Ghana, Cameroon, Gambia, and the Ivory Coast. They included clinicians currently providing

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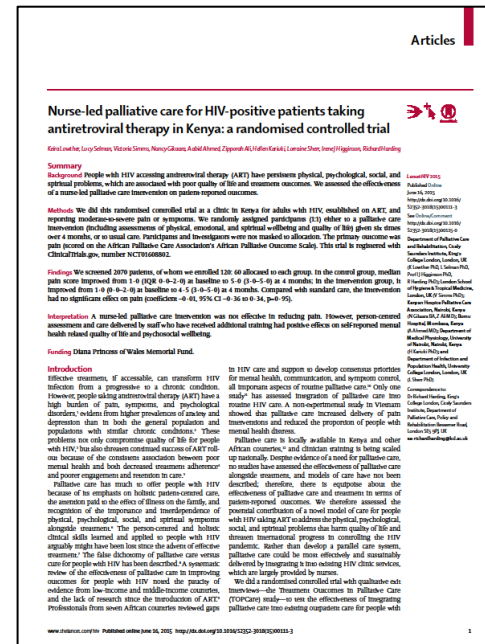
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Intervention studies

Trial Findings 1: TOPCare

Integrated palliative care alongside HIV treatment

- TOPCare
- 2 week training and mentorship for existing ART nurses in HIV clinics
- Holistic assessment & care planning
- Significant impact on:
 - Mental health QoL ($p=0.01$)
 - Psychiatric morbidity ($p=0.004$)
 - Palliative care problems (psychosocial) ($p=0.002$)



Lowther et al 2015 Lancet HIV

Trial Findings 2: Breathlessness

- Randomised controlled trial of Breathlessness Intervention Service (BIS)

(Lancet Respiratory Medicine 2014)

- short-term, single point of access service integrating palliative care, respiratory medicine, physiotherapy, and occupational therapy
- Mastery in BIS group improved compared with the control (mean difference 0.58, 95% CI 0.01-1.15, $p=0.048$; effect size 0.44).
- Survival to 6 months better in BIS than control (50 of 53 [94%] vs 39 of 52 [75%]) and in overall survival (generalised Wilcoxon 3.90, $p=0.048$).

Conclusions

- Person-centred care requires
 - PCOMs/PROMS
 - Goal attainment scaling Turner Stokes
 - Enables costing and outcomes assessment
 - UK wide for every episode of rehab inc HIV Mildmay
 - *BMJ Open 2016*
 - Can existing HRQoL measures direct care?
 - Content validity ?
 - 2016 developing a UK HIV PROM