Practical use of APCA African POS: research and audit

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Development and validation of APCA APOS

• Importance of locally relevant outcome measure to describe impact of palliative care in Africa
• South African setting
• Translation into isiXhosa, isiZulu, Afrikaans
• Discussion about concepts – what does at peace mean, how do we find the correct words to convey the concept (face validity)
• Construct validity comparing MVQoLI and APCA African POS
• User’s manual guides the procedure for audit or for research
APCA APOS manual

• Training of hospice staff or research staff
• Follow manual in step by step procedure
• Using role play as experiential training assists users to understand the impact of the questions
• In the clinical setting, it was found that questions often stimulated further discussion with patients
APCA APOS as Quality Improvement Programme

The benefits of this quality improvement programme are:

• Improved care to patients and family members
• Documented evidence of the impact of the palliative care service
• Demonstrate effectiveness of care and motivate for expansion of the service.
• Evidence of the effectiveness of palliative care as a discipline.
• Evidence to convince funders and policy makers of the impact of palliative care for patients and family members.
• Included as a measure standard of care
Measurement as a standard

Hospice Palliative Care Standards


African Palliative Care Association
APCA Standards for Providing Quality Palliative Care Across Africa
Practical use of APCA APOS in clinical setting

• HPCA hospices conducted annual audit of care.

• Hospice staff interview 10 patients and family members on admission to the service (most hospice care provided in the home in South Africa); patients are interviewed weekly for the next 5 weeks

• Assess change in patient and family outcomes over 6 week period

• 34 hospices, 298 patients – improved Patient Reported Outcome Measures (PROMs)
Use of APCA APOS in research

• Currently, TB is the condition with the highest mortality rate in South Africa

• To identify what palliative care-related problems do patients with drug-resistant and patients with drug-susceptible tuberculosis experience on admission to hospital?

• APCA APOS used to assess baseline/cross-sectional self report of problems

• Worst problems: the items with worst score responses were worry (60.5%), pain (42.1%), needing help and advice to plan for the future (35.1%), symptoms (29.0%).

• Patients admitted with drug-susceptible TB had more severe pain, symptoms and worry than those with drug-resistant TB.

• Highlight that even patients admitted with anticipated positive treatment outcomes (cure of TB) also require access to palliative care.
Use of APCA APOS in research: Access to PC

• Study assessed access to palliative care either through referral for PC; or receiving palliative care in their current care settings; oncology service; HIV clinics; MND support group.
• There were 162 participants in the study who met the inclusion criteria.
• During the study 43 patients died and only 9 patients were referred to palliative care services.
• Most patient outcomes improved for patients in the HIV clinics, indicating good integration of PC into HIV care; no improvement in PROMs amongst the cohort of oncology patients; nor amongst MND patients.
• There was also a sub-set of patients with HIV and of oncology patients with high pain scores that did not resolve over the study period.
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Use of APCA APOS in research: Quality of care

• A prospective cohort study conducted in hospice and non-hospice organisations (in 5 provinces of SA); convenience sampling of 16 participants per organisation and 9 family members

• Using APCA APOS to evaluate quality of care provided by the NGOs

• 459 patient participants recruited to the study and 253 family members.

• The results of the study show significant improvement in patient reported outcome measures in both hospice and non-hospice sites.
• Hospice

• Non-hospice
In summary, APCA APOS

Usefulness
• Valuable measure to use in audit of service & Quality Improvement Programmes
• Assessment of patient need and quality of care provided to individual patients
• Easy to understand and to administer to all groups
• Telephonic follow-up provides good data

Gaps
• In Africa, social and economic issues are often more pressing (POS-E) economic evaluation
• General question about symptoms: IPOS includes specific symptoms
Views from the field

• 72 delegates, 16 countries
• Addressed the need to measure quality of care
• “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.”
Use of outcome data for paediatric and adult patients in low and middle income countries

Prof. Julia Downing PhD RGN
Chief Executive
International Children’s Palliative Care Network
Professor in Palliative Care, Uganda
Do we need different outcome data in low, middle & high income countries?

• Is the philosophy the same?
• Do we want the same outcomes?
• Do we want the same quality of services?
• Is palliative care service provision the same?
Children’s report: Main findings

• HIV rates in children are high and rollout of ART is limited
• Very little data on childhood cancers in Africa
• There is literature looking at cultural meanings of terminal illness in Africa
• The evidence base for children’s palliative care has not progressed and no measurement tools
• Few models of children’s PC discussed
• Only 5 peer-reviewed papers found
Need for an outcome measure for CPC

- Measurement of outcomes a priority for global research (Downing et al 2015)
- Lancet Commission report (Knaull et al 2017) – *need a rigorous, vigorous & substantive research agenda that provides the tools to measure the outcomes of the care provided*
- APCA C-POS only available measure and still being validated
- Literature review identified 27 potential measures (Coombes et al 2016)
- The Oxford PROMS group concluded there is inadequate attention to children and parent-reported outcome measures
- MRC scoping working report on PROM methods identified two gaps: EoL and childhood issues
APCA African C-POS

- Developed across the region
- Ongoing research into its validation – about to be published
- Informed research in other parts of the world e.g. Europe
- First in the world
Finalisation of the Tool

- Work ongoing on:
  - Utility
  - Acceptability and feasibility
  - Validation and psychometric testing
  - Establishing face, content and construct validity and reliability

- A few questions may be revised
Utilisation of the tool

• Already being used in some contexts
• Being used in clinical practice, as well as research
• Development of the C-POS in different settings: E.g. Uganda, Belgium, France, South Africa....
Lessons learnt

• Challenges re research in CPC
• Definition of CPC/SHS etc
• A child will tell you their concerns if you ask them
• Child and/or proxy reports?
• Different tools for different ages?
• What methods of scoring should be used?
• Outcome tool or assessment tool or both?
• Length of the outcome tool
• Developing an outcome tool takes time
• It won’t be perfect......
Outcome data in LMICs...

• POS – being utilized across the world:
  – in specialist and generalist settings
  – In education to research in order to improve care
  – Successful adaptation for different countries and cultures
  – Important for measuring impact, improving service provision and providing robust evidence

• Over 9,000 users of the POS measures in >20 countries
Examples

• Nepal:
  — Challenge as illness not traditionally discussed

• Brazil:
  — “We found the POS-S Renal patient card was easily understood by patients and should be used routinely to establish measures that improve QoL”

• Kenya
  — Development of an App based on the African POS

• Taiwan
  — IPOS helped a lot. It’s just like a window – through it (medical students) can see what patients might need and it’s a very good tool for learning how to take care of patients”
Thank You!

julia.downing@icpcn.org
Questions to think about

1. Are you providing the best possible palliative care that you can?
2. Are you measuring the outcomes of your care?
3. Is there a tool that you can use/adapt from your setting?
4. Do you need support from someone else to do this?
5. How can we help?
International Palliative Care Measurement Collaborative

Deborah Dudgeon MD, FRCPC
Sr Scientific Lead, Person-Centred Perspective
Collaborative's Mission

To improve patient care through systematic measurement, at point of care, of patient-reported & proxy-reported outcomes within palliative care services.
Collaborative's Goals

• Provide internationally comparable data on the quality of palliative care
• Allow services & countries to identify where & what improvements in palliative care are needed
• Inform understanding if, & how, service innovations & new interventions work for different groups of patients and/or families
Underlying Principles

• Undertake prospective patient-level measurement at point-of-care
• Select domains that reflect what matters most to patients & families
• Start with a small number of high quality data points & build
• Aim for assessment (1 point in time) and outcomes (min of 2 points)
• Ensure applicable across diseases
• Ensure outcomes suited to different settings and sectors
• Work towards benchmarking
• Ensure approach is scalable
Domains & # Measures

- Global – 3
- Health related quality of life – 2
- Physical symptoms – 4
- Psychological symptoms – 5
- Spiritual issues – 2
- Functional status – 5

- Dependency – 6
- Family issues – 3
- Practical/care issues – 1
- Quality of Dying – 1
- Phase of Illness - 1
# Domains Captured and Measures

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<tr>
<th>Measure</th>
<th>Domains Captured</th>
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<tbody>
<tr>
<td>IPOS</td>
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<tr>
<td>EORTC QLQ-C15-PAL</td>
<td>5/11</td>
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<tr>
<td>ESAS</td>
<td>4/11</td>
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</table>
Symptom Screening

- ESAS (0-10) – 6 programs
- IPOS (0-4) – 3 programs
- HOPE-SPCL (none to severe) – 1
- EORTC QLQ-C-15 PAL – (not at all to very much) - 1
Functional Status

• Palliative Performance Scale – 5 programs
• Australian Karnofsky – 3 programs
• ECOG – 2 programs
• Self report ECOG – 1 program
Current Study

- Retrospective analysis of up to 1 year of data
- Time of first contact
- Stratified by site of care – home, palliative care unit, consult team, clinic
- Age, sex, diagnosis
- Intensity of pain, shortness of breath, anxiety, depression
- Functional status
- Time until death (if available)
Summary

• Measurement at point of care in palliative care services is happening internationally
• Similar domains are measured
• Different (but some same) measurement instruments used
• Need to minimize number of different instruments and determine how to compare scores
• Measurement is a necessary tool to improve care
Thank you

FOR MORE INFORMATION:
Deborah Dudgeon
Deborah.dudgeon@partnershipagainstcancer.ca
Outcome measurement: driving up quality around the world

Chair: Professor Richard Harding,
Director of the Centre for Global Health Palliative Care
Cicely Saunders Institute
King’s College London
We share many goals

• Palliative care globally strives to
  1. Educate health care professionals on patient need & best care
  2. Demonstrate effectiveness to funders
  3. Identify the individual patient’s needs
  4. Deliver high quality effective care to patients and families
  5. Assist policy makers to include palliative care

• We cannot achieve this without…
  – patient-level data and evidence,
  – an appropriate measure to collect it
### What is an outcome?

**Outcome** = “the change in a patient’s current and future health status that can be attributed to preceding healthcare” (Donabedian, 1980)

<table>
<thead>
<tr>
<th>INPUT/STRUCTURE</th>
<th>PROCESS</th>
<th>OUTPUT</th>
<th>OUTCOME</th>
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<tr>
<td>Which resources are</td>
<td>How are the resources used?</td>
<td>Productivity or throughput</td>
<td>Change in health status or quality of life attributable to healthcare</td>
</tr>
<tr>
<td>required or used?</td>
<td>Prescription of drugs, use of syringe</td>
<td>Discharge rate, day hospice attendance,</td>
<td>Change in pain levels, improved quality of life, decreased anxiety</td>
</tr>
<tr>
<td></td>
<td>drivers, staff visits, staff</td>
<td>number of drugs/opioids, number of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>meetings/clinics, information etc.</td>
<td>consultations, completed care plans etc.</td>
<td></td>
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</tbody>
</table>
Global partnership www.pos-pal.org

10,000 POS users in 126 countries

Research partnerships & outputs

GlobalCARE academic leaders