Palliative Care through International Collaboration and Partnerships in Research: Creativity in Practice

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Outline

• Need for research
• 10 years of palliative care research in Africa
• Four contributions arising from research:
  • Care
  • Advocacy
  • Policy
  • Capacity
• Gaps and how these might be filled – for discussion!
Need for research?

“Clinical and health service audit and research is desperately needed so that we can establish how best to deliver palliative care in the resource-poor setting, and to establish an information base relevant to the developing world” ……… Dr Merriman

Gwyther E. South Africa: the status of palliative care. JPSM 2002; 24:236-8


• Wealth of need for care in Africa
• Dearth of services / knowledge / organisation
Need for research highlighted by an appraisal of palliative care in Sub-Saharan Africa

- Learning from services and practitioners in the countries
- Analysis of reports, e-mail contacts, consultations
- Wealth of experience
- Dearth of evidence
Survey and analysis of effectiveness - identified need to be able to measure care and have the tools for audit

Survey of 48 end-of-life HIV care programs in SSA\(^1\)

Priorities
- Coverage: expansion v quality, Linkage to health systems
- Research, monitoring, evaluation, audit: tools and skills

\(1\) Harding et al BMC Public Health 2003; 33:3

Systematic review of effectiveness: 32 studies (5 Africa – weakest evidence)\(^2\)

Home palliative care and hospice care (multi-professional, trained staff) improve: Pain and Symptom Control, Anxiety, Insight, Spiritual wellbeing

\(2\) Harding et al, Sexually Transmitted Infections 2005; 81:5-14
Workshop to consider what a measurement tool might look like and its properties

Tool is needed to capture:

- HIV and Cancer concerns
- Patients and families
- Children and adults
- Different disease stages and
- Work / used alongside ART
- Be validated in Africa

Measuring and improving palliative care in South Africa: multiprofessional clinical perspectives on development and application of appropriate outcome tools

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Background: Despite innovation and expanding coverage of specialist palliative care provision in South Africa, there have been no multidimensional outcome measures to inform patient monitoring, service evaluation or quality audit. Aim: To identify South African palliative care providers' recommendations on the design, development and utilisation of multidimensional palliative care outcome measures appropriate for the epidemiology and delivery settings for advanced disease in South Africa.

Methods: South African palliative care professionals participated in a review of outcome measures and current use. Participants addressed the objectives of appraisal current practice and setting priorities for the development and application of feasible, acceptable and appropriate outcome measures within the African context.

Results: None of the 32 multiprofessional palliative care participants were currently using a multidimensional palliative care scale. Current practice for monitoring outcomes relied on the use of unvalidated scales, longhand note taking, and use of clinicians’ recall of previous health status. Recommendations for future measures included selecting items that take account of the family burden of disease, the differences between HIV and cancer patient trajectories, and the psychosocial burden of advanced disease in South Africa. Adequate resources should be allocated to staff training to familiarise them with measure use, service infrastructure to be able to utilise outcome data, and ensuring acceptability and appropriateness among patients and families in terms of language, translation and identifying mechanisms to standardise data collection.

Conclusions: Recommendations have been generated from the data, addressing: (i) service enablement for applied and translational research; (ii) validation within South Africa; (iii) development of tools equally applicable to HIV and cancer but separate tools for children; (iv) inclusion of family domains; and (v) support for staff to implement tools. The design of multidimensional outcome measures using this guidance is timely to evaluate and inform current practice, and to guide future funding and service development.

Keywords: HIV, cancer, outcomes, outcome measures, sub-Saharan Africa, South Africa

The epidemiology of HIV and cancer in South Africa demonstrates a clear public health need for palliative care expansion. UNAIDS estimated the South African HIV prevalence to be 18.9% in 2005 (1). The WHO estimates that there are more than 0.5 million annual deaths from cancer in Africa, and cancer rates in Africa are expected to grow by 440% over the next 50 years (2).

APCA African POS

Development
• 11 sites in 8 African countries
• Content & consensus validity (International expert panel, staff interviews)
• Sensitivity to change for item pool (n=100 pts)
• Powell et al *Journal Pain Symptom Manage* 2007; 33:229-232

Validation
• University of Cape Town, School of Medicine/St Lukes Hospice
• University of KwaZulu Natal, Nelson Mandela Medical School/Philanjalo Hospice
• University of Witswatersrand/Wits Palliative Care
• South Coast Hospice
• Hospice Africa Uganda/Makerere University
• KCL - Financial support from: Cicely Saunders International, Big Lottery UK
Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale

Health and Quality of Life Outcomes 2010, 8:10

Richard Harding¹, Lucy Selman¹, Godfrey Agupio², Natalya Dinat³, Julia Downing⁴, Liz Gwyther⁵, Thandi Mashao⁶, Keletso Mmoledi³, Tony Moll⁷, Lydia Mpanga Sebuyira⁸, Barbara Panjatovic⁹, Irene J Higginson¹

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 Missoula-Vitas Quality of Life Index (Spearman’s rank tests); 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 = 90 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 = 285); 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 last address the omissions of palliative care research in Africa.
### APCA African POS

- **10 Questions**
- **Developed in Africa**
- **Used basis of original POS**
- **Developed in 8 centres in UK**
- **Used in many countries**
- **Questions 1-5, 7, 10 very similar to original POS**

- **ASK THE PATIENT**
  - **Q1** Please rate your pain (from 0 - no pain to 5 - worst/overwhelming pain) during the last 3 days
  - **Q2** Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?
  - **Q3** Have you been feeling worried about your illness in the past 3 days?
  - **Q4** Over the past 3 days, have you been able to share how you are feeling with your family or friends?
  - **Q5** Over the past 3 days have you felt that life was worthwhile?
  - **Q6** Over the past 3 days, have you felt at peace?
  - **Q7** Have you had enough help and advice for your family to plan for the future?

- **ASK THE FAMILY CARER**
  - **Q8** How much information have you and your family been given?
  - **Q9** How confident does the family feel caring for ____?
  - **Q10** Has the family been feeling worried about the client over the last 3 days?
APCA African POS

Can use POS with confidence because
• comes from ground up
• many settings
• many countries
• wide applicability
• wide uptake
• published in peer review journal – which has high quality papers.
Four contributions from partnership research and available measure

1. CARE
   • E.g. ENCOMPASS – project – (Big Lottery – UK supported)
   • five full clinical audit cycles in different settings
   • Each site decided their own quality improvement plans,
   • Identified ways to improve care
   • Audit was internally lead in African services
   • Employed and developed teams in Africa
Some ENCOMPASS collaborators

Agupio G, Mpanga-Sebuyira L, Amery J at Hospice Africa Uganda
Mmoledi K & Dinat N at Wits Palliative Care
Goring D & Panatovic B at South Coast Hospice
Mashao T & Gwyther L at St Luke’s Hospice/HPCA
Nkabinde T & Moll T at Philanjalo Hospice
Selman L & Harding R at King’s College London
Application of tool in 5-centre full clinical audit n= 1001 pts, 772 carers

• Each site 100 new pts 6 visits for each of 2 cycles

 Targets:
Statistically significant improvement in symptom score by T2
- ✓ Achieved

-Mean patient worry and family worry score of ≤2 by T2
- ✓ ✓ Exceeded
Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study

Lucy Selman, research associate,1 Irene J Higginson, professor,1 Godfrey Agupio, research nurse,2 Natalya Dinat, director,3 Julia Downing, deputy executive director,4 Liz Gwyther, senior lecturer,5 Thandi Mashao, research nurse,6 Keletso Mmoledi, palliative care service team leader,3 Anthony P Moll, chief medical officer,7 Lydia Mpanga Sebuyira, head of training department,8 Barbara Panajatovic, chief executive,9 Richard Harding, senior lecturer1

Setting Four palliative care services in South Africa and one in Uganda, covering rural, urban, and peri-urban locations.

Participants 90 patients and 38 family caregivers enrolled in palliative care services; 28 patients had cancer, 61 had HIV infection (including 6 dual HIV/cancer diagnoses), and 1 had motor neurone disease.

Conclusions Lack of information was a major theme for both patients and carers, who had important unanswered questions relating to living with a progressive incurable disease. Evidence based recommendations for clinicians are presented, including the proactive provision of information tailored to individual patients and families.

Results Five themes emerged from the data. (1) Information sources: a lack of information from general healthcare providers meant that patients and caregivers had to draw on alternative sources of information. (2) Information needs: patients and caregivers reported needing more information in the key areas of the causes and progression of the disease, its symptoms and treatment, and financial/social support. (3) Impact of unmet needs: poor provision of information had a detrimental effect on patients’ and caregivers’ ability to cope. (4) Communication: negative experiences of communication with general healthcare staff were reported (misinformation, secrecy, insensitivity). (5) Barriers to effective provision of information: barriers related to symptoms, culture, time constraints in hospital, and paternalism in general health care.
‘The search for meaning is not only a challenge of patients and families.

As individuals and as a caring team, many workers feel compelled to seek answers or, more often, to develop a readiness to live with questions.’

• Exploring spiritual dimensions of care from care providers and patients

• Pan African expert group has worked with us to develop the spiritual care recommendations – which we are launching at this meeting

• Supported by Sir Halley Stewart Trust
Example of learning from Africa

- Spiritual care recommendations developed from qualitative interviews with 72 patients in four palliative care services, with 21 African care providers, and data collected in ENCOMPASS on 285 patients

- AB043 – 10.45am today – Selman, Agupio, Dinat, Downing, Gwyther, Harding, Higginson, Mmoledi

- In addition to African report – also is UK based version on recommendations for spiritual care of African people living in UK
2. ADVOCACY – providing the evidence

• **Proving** that palliative care needs are highly prevalent in population and their nature
  • Murray SA, Grand E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their caregivers. BMJ 2003; 326: 368
  • Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. BMJ 2003; 327: 192-4
  • Grant E, Murray SA, Brown J. A good death in rural Kenya? J Pall Care 2003; 19: 159-67
  • Paper from Tanzania shows that HIV outpatients had high levels of palliative care need – irrespective of ART use (AIDS Care, Harding et al 2008)
  • Data from S Africa and Uganda showing multi-dimensional pain and symptom burden (European Journal of Cancer, Harding et al in press)
ADVOCACY – providing the evidence

• **Proving** that care is effective – what can be improved for patients and families by palliative care
  • Examples of improvement in dimensions of care as assessed by the APCA POS

• **Proving** a commitment to quality improvement – led by services themselves
  • African services leading the quality improvement

• POS Tool was lobbied to various regions within S Africa – and now is standard tool for use in clinical care
PEPFAR – Evaluation of care

• Partnership of APCA, KEHPCA (Kenyan Hospice Pall care association), University of North Carolina, US Government, Kenyan and Ugandan country teams, 12 clinical sites.
• Cross-sectional survey of facility configuration and activity
• Longitudinal evaluation of existing care, focusing on patient outcomes identifying and following trajectories of palliative care
• Patient, family and professional and pharmacy data, and costing data
Preliminary reports from PEPFAR

• Pain prevalence versus availability of opioids – Simms, Penfold, Namisango, Powell, Downing – presented today 2.30pm AB073

• In one of countries
  • Of the five categories of PEPFAR Care & Support (clinical, psychological, spiritual, social and preventive), 99% of participants received clinical care and 94% prevention.
  • Psychological care was the least commonly delivered (58%)
  • Biggest problems on the multidimensional care scale (APCA African POS) were not being able to share their feelings with anyone, and not having enough help and advice for the family to cope

• Multidimensional palliative care related problems during the first 3 months after diagnosis – what are they and how common? – Simms, Namisango, Penfold, Downing, Powell, Harding – presented today 2.30pm AB079

• Longitudinal palliative dimensions in HIV care (BMC Public Health 2010)
3. Policy

- Evaluation of the Ugandan Opioid public health programme and demonstrating its success (*Logie and Harding BMC Public Health* 2005, 5:82)


- Symptom prevalence shows need for drugs and potential effectiveness of treatment

- Discussed with INCB competent authorities within Ministries of Health to show difference between what available and what thought was available
PRISMA Work Packages (WPs)

- **Public priorities and preferences for end of life care WP2**
  - Optimising responsiveness in research

- **Cultural difference in end of life care WP1**
  - Optimising cultural sensitivity in research
  - Optimising clinical relevance in research

- **Clinical research priorities in end of life care WP3**

- **Review and recommendations for the best practice and resources for the use of end of life care quality indicators: measurement tools currently in use, focusing on POS/STAS WP4**
  - Reinforcing measurement in symptoms
  - Reinforcing measurement in vulnerable groups of people

- **Best practice in symptom measurement WP5**
  - Pedro Lopes Ferreira

- **Best practice in measurement in nursing homes WP6**

- **Final conference WP8**
  - Noel Derycke
PRISMA – an EU funded collaboration

9 European countries and APCA

• WP1 – contribution to understanding cultural aspects of measurement, study in Kenya – link to international network (AB103 Downing et al, 2pm Thursday)

• WP2 - Street survey – 201 people in Nairobi – priorities for care - link to telephone survey in all European countries (AB102 Downing et al, 11.30 today)

• WP4 - On-line survey of outcome measure use among clinicians – need for support and training (AB099, Downing et al 12.25 today)
Building capacity

- Training research nurses and staff in Africa – who stay in Africa
- Training staff in better assessment and care
- Raising the perceived importance of palliative care
- Scientific co-ordination – e.g. PRISMA – because Africa has taken such a lead in measurement it’s a key member of PRISMA
- Open Society Institute Leadership Programme
Long lasting capacity – training the future leaders
Sir Halley Stewart Trust MSc fellowships

• Support towards 2 people based in Africa to take MSc in Palliative Care at King’s College London Learning taught in 2 week modules (6) over 2 years, PLUS a research project based in Africa but supervised from UK

• Opportunity to interact with individuals in palliative care from across the globe
• Funding for travel, fees, books
• First awards to Eve Namisango, Jacinto Amandua
• Hope to make annual – but need other supporters – and to develop to PhD training

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International clinical academic partnerships

- African POS
  - Provincial Depts of Health
  - PEPFAR USAID and UNC 1200 pts
  - DFID Kisumu Kenya evaluation
  - Observational study rural Tanzania, U Maryland Inst Virology

- Health Services / Effectiveness Research
  - Evaluation Ugandan Morphine Public Health Programme
  - Multimethods demonstration opioid safety & effectiveness

- Prevalence of HIV palliative problems rural Tanzania
  - *AIDS Care*. 2007, 19:1304-1306
  - Investigation into communication and patient outcomes Cuba
  - *J Pain Symptom Manage* In Press
• Cicely Saunders Institute
  • Centre of excellence: integrated research, education, information provision and clinical care
  • Hub International Research
    – Video Conferencing Facilities
    – Teaching suites & theatre
    – Information and support centre
    – Clinical palliative care and cancer staff, interview rooms and clinical/consultation rooms
    – Space for trialling therapies

ANY life-limiting incurable disease…..
Cancer, HIV, Neurological, Stroke, Renal failure, Chronic Heart Failure, COPD
According to NEED not DIAGNOSIS or PROGNOSIS
Alongside potentially curative / life prolonging treatments

“Person centred”
Translational focus: developing & testing (cost) effective interventions
Gaps – better science, better care?

1. Is palliative care is offered to all those in need?
2. Is it fully recognised and funded by policy makers?
3. Are you sure we have the most effective and cost-effective models of care?
4. As clinicians you are sure that you are offering effective treatments and care for all the problems and symptoms patients/families experience?
5. Is capacity as you want it to be?
Better science, better care?

• Sadly there are more failed than successful studies in palliative care – all over the world
• Running successful research takes: scientific knowledge, expertise, practical knowledge, careful planning, persistence, good luck, ability to recognise and adapt to change, collaboration, a team of all the strengths needed at the outset, communication of the findings, implementation
• Common failings in research are over-optimistic aims, unclear aims, collecting too much inappropriate information on too few people
Building better sustained care through better science requires:

• Fill the gaps for policy makers and advocates
  • Robust evidence routine care and in trials
  • Cost effectiveness studies
  • Paediatric palliative care – outcomes and evidence

• Fill the gaps for patients and families
  • Better treatments and care – testing the many innovations
  • Improved access to care for those hardest to reach
  • Sustainable models of care
Building better sustained care through better science needs:

- Fill the gaps for capacity
  - Post-graduate education
  - Training fellowships – for people in Africa to train where this can be most quickly achieved – MSc and PhD level, for nurses, doctors and other professionals

- Fill the gaps for partnership
  - Mentorship – ongoing relationships are needed with experts
  - Collaborative research – with African members partnering with and leading aspects of the work
Summary

• An impressive increase in successful research in African in the last decade
• Spurred by development of APCA African POS - validated and relevant for Africa
• Research contributes to: Care, Advocacy, Policy and Capacity
• Gaps – knowledge for evidence, of models of care, improved access, treatments for symptoms / problems that continue
• Conducting research – not easy – needs many attributes
• International partnerships in palliative care have been creative and fruitful
• Need now
  • Fill gaps for evidence for policy makers and patient care
  • Capacity building in research at all levels, training fellowships – leading to MSc and PhD
  • Continuing mentorship and Collaboration
• Better science – better care
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For copy of presentation/more information

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References


