

Clinical academia for global health: TRANSLATIONAL PALLIATIVE CARE RESEARCH

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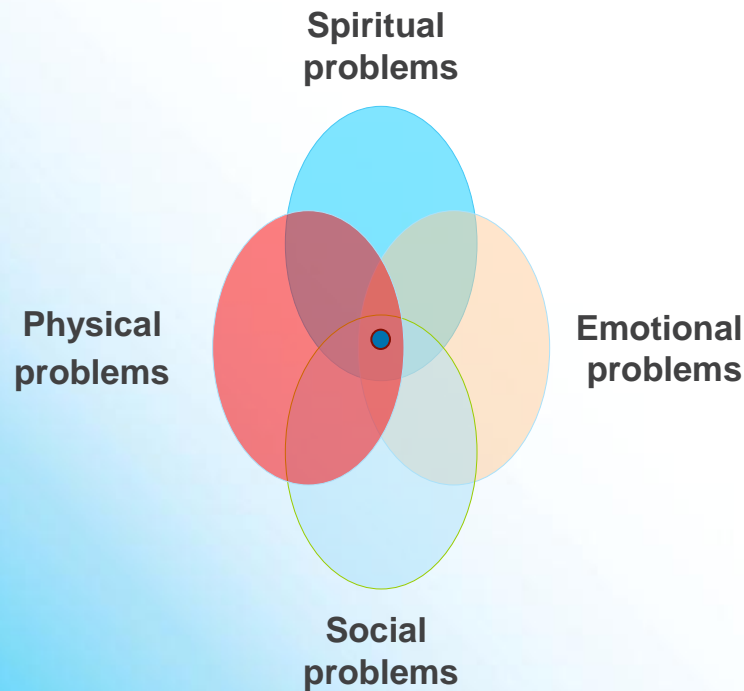
Dept of Palliative Care Policy and Rehabilitation
www.kcl.ac.uk/palliative



Generating evidence to improve patient outcomes

1. **Epidemiology & need**
2. **Current activity: translational palliative care research in developing settings**
3. **The future: integrated teaching, research and clinical practice**

Palliative care for global public health



•Essential and effective palliative care

–Component from diagnosis (WHO)

– Improves outcomes for patients and families facing life limiting progressive disease

- Higginson et al *Journal Pain Symptom Manage* 2003;25:150-168

- Harding et al *Sex Transm Infect* 2005;81:5-14

–Evidence generated in industrialised countries

•Sub-Saharan Africa

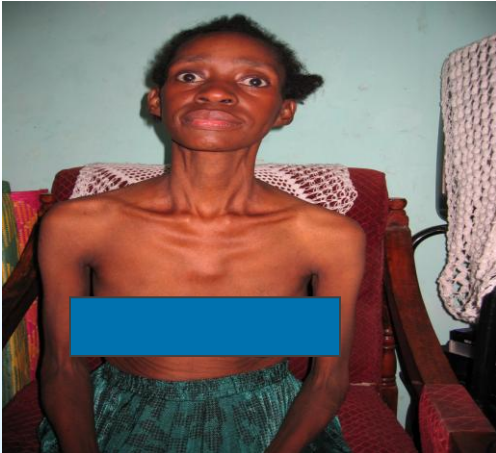
–HIV 22.5m living & 1.6m deaths in 2007 (UNAIDS)

–Cancer 0.5 million deaths, 70% of global cases by 2020 (WHO/UN)

–? heart failure, XMDR TB, neurological, older people

–? Asia, Eastern Europe

Translational or translatable research? Appraising the evidence



Carcinoma cervix & HIV



Patient's carer – aged 7

Harding & Higginson, *Lancet*

2005; 365:1971-1977

Review

Palliative care in sub-Saharan Africa

Richard Harding, Irene J Higginson

Summary

Control of pain and symptoms and terminal care are necessary for quality HIV and cancer care in sub-Saharan Africa. However, what constitutes feasible, accessible, and effective palliative care, and how to develop such services, remains to be resolved. Africa-specific palliative care includes components that carry resource implications. Home and community-based care has been largely successful, but community capacity and the resources and clinical supervision necessary to sustain quality care are lacking. Coverage and referrals must be primary concerns. Simple lay and professional protocols have been developed, but opioid availability remains a major constraint. Areas of good practice, and areas where further success may be achieved include: attention to community needs and capacity; explicit frameworks for service development and palliative care integration throughout the disease course (including antenatal provision); further education and protocols; strengthening and dissemination of diverse referral and care systems; increasing advocacy; and funding and technical skills to build audit and quality assessment.

Background

In 2003, there were an estimated 26.6 million people in sub-Saharan Africa living with HIV, 3.2 million new infections, and 2.3 million AIDS-related deaths.¹ Additionally, WHO estimates that there were 0.5 million deaths per year from cancer in Africa,² and that by 2020, 70% of new cancer cases will be in the developing world.³ Cancer rates in Africa are expected to grow by 400% over the next 50 years.⁴ Palliative care has gained broad support as an important part of disease management,⁵ and the WHO African Initiative has established the principle that palliative care is "in the framework of continuum of care from the time the incurable disease is diagnosed until the end of life".⁶

Late presentation, inadequate diagnostic facilities and assessment skills, poor availability of chemotherapy and radiotherapy, and absence of opioids all increase the need for adequate cancer pain control in Africa.^{7,8} Home-based care has been the most common service model in Africa, although home-care providers are often inadequately trained in clinical skills and lack access to essential drugs.⁹ However, clinical, nursing, and lay education in terminal care have been achieved in a small number of places for some time (from 1983 at Island Hospice Zimbabwe), and many achievements have been made in education at professional levels.¹⁰

Although advocacy and lobbying activity for cancer pain control in developing countries has been continuing for some time,¹¹ palliative care has been focused on developed countries.¹² What constitutes feasible, accessible, and effective diverse models in Africa, and how to develop such services, remains to be resolved.¹³ To inform the growing funding and development focus on palliative care in Africa, we aimed to describe the African context for palliative care, identify factors that lead to sustainability, maximum coverage, and efficient referral systems, and highlight examples of good practice through analysis of models of palliative care and evaluation findings.

During 2003, funders, non-governmental organisations, associations, and practitioners involved in

Panel: WHO definition of palliative care¹⁴

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

palliative care in African countries were asked to provide existing prepared reports on their activities. Electronic mailing lists and websites that promote and facilitate palliative care services in Africa (eg the International Association for Hospice and Palliative Care, Worldwide Hospice and Palliative Care Online) were posted with requests for information. From the scientific and unpublished work, service and research data were extracted and reviewed with respect to models, development, lessons, and findings (panel).

Results

We identified 26 palliative care service organisations, which were described in 38 reports. Research, monitoring, and evaluation findings from 15 studies were reported by eight organisations. A further 169 relevant publications and reports were included. The full review and extraction tables with reference lists are available to download free of charge.¹⁵

Search strategy and selection criteria

We used a combination of a systematic review and documentary analysis. We searched biomedical databases with supplementary hand searches in July 2003. We searched MEDLINE (1966–2003), CINAHL (1982–2003), AMED (1985–2003), CancerLit (1975–2003), PsycInfo (1974–2003), EMBASE (1980–2003), Science Citation Index (1981–2003) and Social Sciences Citation Index (1981–2003). Search terms were the union of "hospice", "terminal care", "terminally ill", "palliat*", "hospice*", "dying", "end of life", "advanced disease", "sustainability", and "coverage" together with the union of all named sub-Saharan African countries and Africa.

Lancet 2005; 365: 1971–77
See Comment page 1909
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Development of a translational African research programme

1. Identification of research priorities among end of life practitioners

- Electronic survey, 48 facilities in 14 countries
- Need reported for tools and measures to improve care (Harding et al *BioMedCentral* 2003; 3:33)

2. Clinician focus groups to inform outcome measure development

- Apply to cancer, HIV, poor literacy, ART treatment and family burden of disease
- Harding et al *Progress Palliative Care* 2007; 15:55-59.

3. Protocol applying scientific principles to develop & validate outcome scale

- POS developed in UK (Higginson et al *Qual Health Care* 1999; 8:219-227)
- KCL applied methods to international versions
 - Argentinean: Eisenclas et al *Journal Pain Symptom Manage* 2008;35:188-202.
 - Dominican Republic/Cambodia: Pappas et al *BMC Palliative Care* 2006, 5:3.

APCA African POS

1. 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

2. Validation

KCL (lead)

Cicely Saunders International

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

Validation protocol: 682 pts, 437 family carers, 8 languages

- **Face validity: cognitive/qual interviews with 122 pts**

- Pt and family needs mapped well onto POS domains, communication & information; family needs; symptoms; psychological well-being; spirituality

- Sound user interpretation of items

- Selman et al, *BMJ* in press

- **Construct validity: comparison to MISSOULA VITAS 285 PTS**

- As hypothesised low to moderate Spearman's Rank 0.57 for total scores

- **Internal consistency: 307 pts**

- As hypothesised for a multidimensional tool, moderate Chronbach's Alpha 0.6

- **Test-retest reliability: within 24 hours 307 pts**

- High intraclass coefficient 0.89 for total score

- **Time to complete (285 pts)**

- Brief, median 7 mins and 5 minutes on successive visits

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

Cycle 2 targets

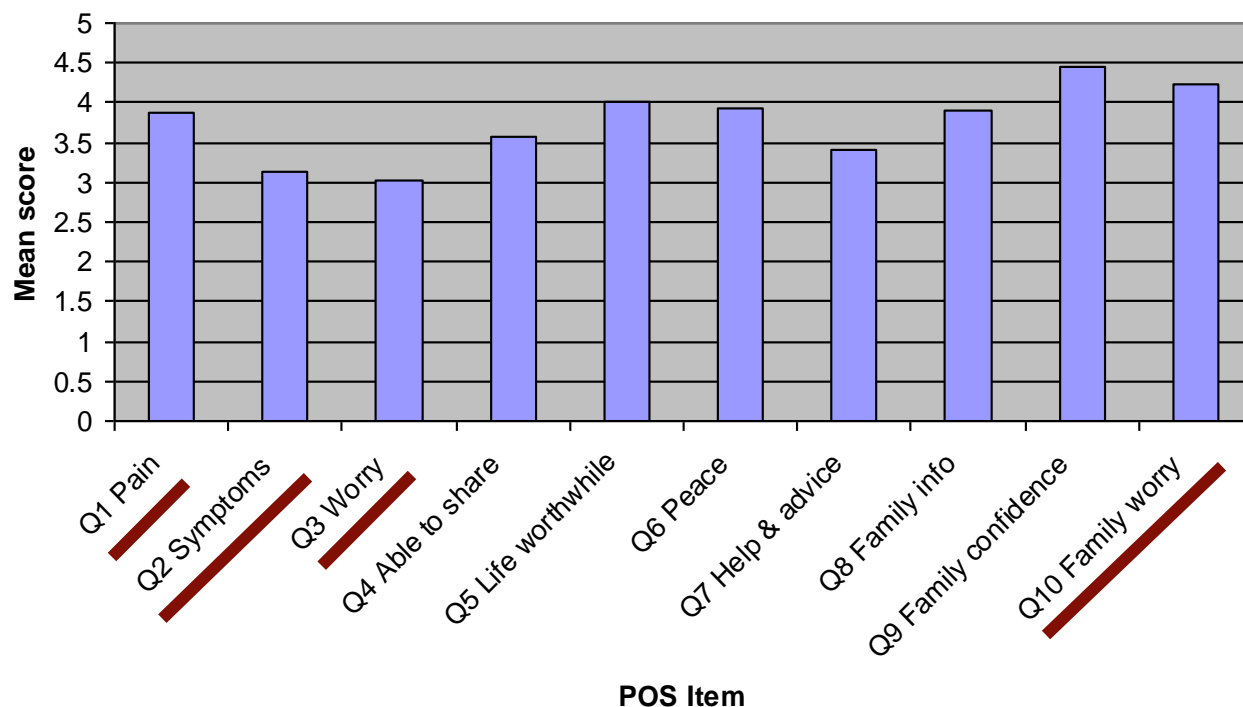
Statistically significant improvement in **symptom** score by T2

- ✓ *Achieved*

Mean **patient worry** and **family worry** score of ≤ 2 by T2

- ✓ *Exceeded* – achieved by T1 for both patient & family worry

POS baseline scores



Clinical academic partnerships

•African POS application

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

•Health Services Research

- Evaluation Ugandan Morphine Public Health Programme
Multimethods demonstration opioid safety & effectiveness
BioMedCentral Public Health. 2005, 5:82.
- 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



Methodological development & good practice in global partnerships

- Development of respectful partnerships & devising the agenda
- Development of indigenous individuals/scholarships
- Cultural competence (PhD investigations)
- Methodological developments (Harding et al *J Pain Symptom Manage* 2008; 36:304-309)
- Fostering cultures of investigation
- EU FP7 PRISMA- international collaboration in measurement
- Facilitating South-South partnerships
- Data demand and utilisation

Future potential for Global Health partnerships in AHSC

- Integration of research, teaching and care: Cicely Saunders Institute
- Access to teaching and technologies
- Career paths, PhD training
- Further methodological development
- WHO collaborating centre status
- MSc alumni

