

Advocacy for palliative care

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Outline

- What is advocacy?
- What is palliative care?
- Why do we need palliative care for HIV patients?
- An HIV clinician's perspective
- The need for palliative care
- Have you ever experienced pain?
- A success story
- Who are the advocates for palliative care?
- Petition to the SA Minister of Health

Definition of advocacy:

It is the act of arguing on behalf of a particular issue, idea, person or animal:

Political advocacy:

Influencing political decisions and policy makers

Legal advocacy:

Speaking in court on behalf of clients

Social advocacy:

Speaking on behalf of vulnerable groups e.g. palliative care patients

What is palliative care?

- The relief of suffering
- Who defines this suffering?
- Patient centred, holistic care
- HIV clinicians

WHO Definition of Palliative Care

Palliative Care is an approach that improve the **quality of life of patients and their families** facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and the treatment of pain and other problems, **physical, psychological and spiritual**
(WHO 2002)

When to start palliative care

- Palliative care is applicable **early in the course of illness**, in conjunction with other therapies that are intended to cure, and includes those treatments that prolong life, as well as investigations needed to better understand and manage distressing clinical complications. (WHO 2002)
- It **begins when illness is diagnosed**, and continues regardless of whether a child receives treatment directed at the disease. (WHO definition of palliative care for children)
- Palliative Care is not only terminal care

3 triggers for palliative care (GSF)

1. Surprise question? – would you be surprised if this patient were to die within the next 6-12 months
2. Patient choice/need – the patient who chooses comfort care only or the patient in special need of supportive or palliative care
3. Clinical indicators
 - General indicators (Specific indicators)
 - Weight loss - Greater than 10% weight loss over 6 months
 - General physical decline
 - Serum Albumin < 25 g/l
 - Reducing performance status

Why do we need Palliative care for HIV patients?

- Complex care needs in HIV
- Symptom burden patients on HAART attending outpatient HIV clinics in London
 - 63% tiredness/fatigue
 - 55% worry
 - 51% diarrhoea
 - 50% pain
 - 47% skin problems
 - 46% numbness/tingling in hands/feet
 - 32% suicidal ideation

ref: Harding et al IJSA 2006;17:400-405

Mortality data

(WHO global burden of disease 2011)

- Total deaths SA (2008) 668,000
- HIV related deaths (2008) 263,000
- 40% deaths

- Did these people receive palliative care to ensure physical comfort and emotional & spiritual support as they were dying?
- Have their families received bereavement care?

An HIV clinician's perspective

Extent of PC Needs in PLHIV

- 50% have identified PC need
- 8-18 symptoms at one time
– even on ART



Loss to care

- Concerns about mortality rate and loss to follow up
- Boulle et al: 7 yr study in Khayelitsha, South Africa report that 35.3% of a cohort of 7323 adult patients were lost to care at 5 years, combining mortality and LTF
- Green: symptom assessment & palliative care for people living with HIV (PLHIV) leads to improved quality of life and contributes to HAART adherence
- Re-engineering of PHC treatment support in the patient's home
- CHW not equipped to assess & manage distressing symptoms

Palliative care needs in HIV

Needs	Stages I-II	Stage III	Stage IV	ART
Pain	28-51% prevalence	62-89% prevalence	60-98% prevalence	29-74% prevalence
Other Symptoms	--	Other symptoms <ul style="list-style-type: none"> • Itchy/dry skin: 34-72% • Fatigue: 60-85% • Insomnia: 40-55% • Neuropathy: 30-59% • Anorexia: 32-63% • Cough: 27-60% 		Other symptoms: <ul style="list-style-type: none"> • Itchy/dry skin: 23-38% • Fatigue: 33-79% • Insomnia: 35-63% • Neuropathy: 16-66% • Anorexia: 9-36% • Cough: 26-45%
Depression and sadness	43% depressed	40-54% depressed	63% depressed 43-82% sad	38-57% depressed 78% sad
Anxiety, stress and worry	--	36-40% anxious	63% anxious 51-86% worried	31-43% anxious 82% worried 34% with post-traumatic stress disorder 43% with acute stress disorder

Source: Data from studies in Africa, Asia, Europe and North America – thanks to Kim Green for this slide

Benefits of including palliative care as standard care in HIV

- Improved treatment adherence
- Improved patient outcomes
- Fewer emergency visits to health care facility
- Fewer re-admissions to hospitals
- Lower health care costs

Integrate palliative care into HIV care as part of standard care

- Hospital based palliative care – all health care workers trained in palliative care; palliative care clinicians as part of multi-disciplinary team; PC consult team eg Gauteng Centre for Excellence in Palliative Care at CHBH (Hongoro, Dinat A cost analysis of a Hospital-based Palliative Care Outreach program. JPSM June 2011 41(6) 1015-24
- Community Health Centres/ clinics: Abundant Life Programme – patients and family members attend fortnightly support group, learn about their condition and about self care (in press, Cupido, van Niekerk, Gwyther, Harding. Abundant Life Programme at district hospital)
- TOPCare study

Integrate palliative care into HIV care as part of standard care

- Continuity of care into the community
- Palliative care in the home
- Quality of care in home care programmes
- Home-based carer with supervision & support of professional nurse and back-up of multidisciplinary team



Have you experienced pain?

Have you experienced pain?

- Group 1
- Describe your pain experience to your partner

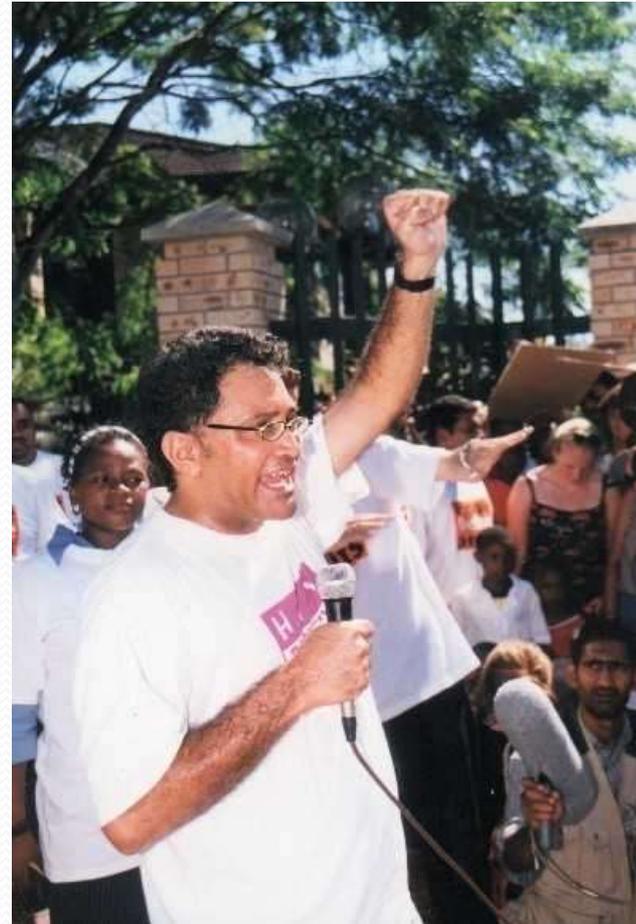
Have you experienced pain?

- Group 1
 - Describe your pain experience to your partner
- Group 2
 - You are a busy clinician in HIV clinic focused on patient response to treatment
 - You are distracted, writing notes, answering your phone, deciding next steps in treatment
 - Do not make eye contact with your partner

Pain assessment

- Listen to your partner's narrative
- Ask them to describe the pain, what does it feel like, how bad is it rated against the worst imaginable pain, does it radiate anywhere, what makes it better, what makes it worse? When did it start, is it constant or intermittent?
- Does it interfere with their normal daily activities?

An advocacy success story: TAC



Campaign for access to palliative care

- Who are the advocates for palliative care?
- “Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”
(Chochinov, 2000)

SA Patients' Rights Charter

- Everyone has the right to access to
- “provision for special needs in the case of... patients in pain”
- “palliative care that is affordable and effective in cases of incurable or terminal illness”

Petition for access to palliative care

- HPCA Petition : calling on government to ensure that palliative care is accessible, available and affordable to South Africans facing advanced illness, and to ensure that at the end of their lives patients are treated with dignity and experience relief of suffering
- Implementation through WHO public health approach:
 - Training of all health professionals in palliative care
 - Access to palliative care medication
 - Palliative care policies in health & welfare sectors

Conclusion

- Ensure you have the knowledge and skills to provide palliative care to patients throughout the continuum of the illness
- Ensure your facility has essential palliative medicines in stock
- Link with community-based palliative care services
- Sign the petition www.hpca.co.za

Clinical
Guidelines for
Palliative Care



Hospice
Palliative
Care
Association
of South Africa



Paediatric
Palliative Care
Guidelines



bigshoes
a promising future



Hospice
Palliative
Care
Association
of South Africa



Guidelines
for Providing
Palliative Care
to Patients with
Tuberculosis



Hospice
Palliative
Care
Association
of South Africa



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Thank you for your attention

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PALLIATIVE
CARE
IS A HUMAN RIGHT

CARE
LIFE

NO PAIN

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