Palliative Care in HIV

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What is palliative care?

- The relief of suffering
- Who defines this suffering?
- Compassionate holistic patient centred care
- Responding to patient and family needs
- Comprehensive care & support
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
Integrating palliative care into HIV care

- Peter Selwyn: “In the early years of the AIDS epidemic in the developed world, AIDS care was palliative care”
- Focus on treatment --> “loss of perspective on chronic disease and the issues relevant to progressive, incurable illness and end of life care”

Why should we care about palliative care for AIDS in the era of antiretroviral therapy? *Sex Transm Infect* 2005 81: 2–3
In HIV care palliative helps to improve quality of life, enhance adherence to HAART and other therapies, and addresses the complicated psychosocial issues faced by people living with HIV and their families.
HIV care should not be “either...or – either palliative or disease specific therapy – but ‘both...and” integrating both paradigms in the comprehensive care of patients with AIDS.
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
- TB 19,500

Did these people receive palliative care to ensure physical comfort and emotional & spiritual support as they were dying?

Have their families received bereavement 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, how frequently can CHWs visit?

CHW not equipped to assess & manage distressing symptoms
# Palliative care needs in HIV

<table>
<thead>
<tr>
<th>Needs</th>
<th>Stages I-II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>ART</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>28-51% prevalence</td>
<td>62-89% prevalence</td>
<td>60-98% prevalence</td>
<td>29-74% prevalence</td>
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<tr>
<td>Other Symptoms</td>
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<td>Other symptoms</td>
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<td>Other symptoms:</td>
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<tr>
<td></td>
<td></td>
<td>• Itchy/dry skin: 34-72%</td>
<td></td>
<td>• Itchy/dry skin: 23-38%</td>
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<tr>
<td></td>
<td></td>
<td>• Fatigue: 60-85%</td>
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<td>• Fatigue: 33-79%</td>
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<tr>
<td></td>
<td></td>
<td>• Insomnia: 40-55%</td>
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<td>• Insomnia: 35-63%</td>
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<tr>
<td></td>
<td></td>
<td>• Neuropathy: 30-59%</td>
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<td>• Neuropathy: 16-66%</td>
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<tr>
<td></td>
<td></td>
<td>• Anorexia: 32-63%</td>
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<td>• Anorexia: 9-36%</td>
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<tr>
<td></td>
<td></td>
<td>• Cough: 27-60%</td>
<td></td>
<td>• Cough: 26-45%</td>
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<tr>
<td>Depression and sadness</td>
<td>43% depressed</td>
<td>40-54% depressed</td>
<td>63% depressed</td>
<td>38-57% depressed</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>43-82% sad</td>
<td>78% sad</td>
</tr>
<tr>
<td>Anxiety, stress and worry</td>
<td>--</td>
<td>36-40% anxious</td>
<td>63% anxious</td>
<td>31-43% anxious</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>51-86% worried</td>
<td>82% worried</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>34% with post-traumatic stress disorder</td>
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<td></td>
<td></td>
<td>43% with acute stress disorder</td>
</tr>
</tbody>
</table>

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
Pain management
Management of pain in HIV

- Do we ask about pain?
- Does the clinician and the patient accept that pain is part of the illness?
- Do we treat pain with analgesics?
- Do we anticipate that pain will improve on HAART?
- Are ARVs analgesics?
Management of pain in HIV

- Do we prescribe amitriptyline to treat pain?
- Is amitriptyline an analgesic?
- Do we learn how to assess and manage pain from palliative care?
Pain control

- Assessment of pain, explanation to patient, disease modification
- Pain management according to WHO guidelines
  - by the mouth
  - by the clock
  - by the ladder
- Regular review
WHO 3–step analgesic ladder

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Step 1

Non-opioid +/- adjuvants

Step 2

Weak opioids +/- step1

Step 3

Strong opioids +/- step1
Analgesics

- Step 1 – Paracetamol/aspirin/NSAID
- Step 2 – Tramadol
- Step 3 – morphine
  - mist morphine (4 hrly administration)
  - morphine tabs (rapid release, slow release)
  - morphine sulphate inj (sub-cut)
  - fentanyl (patches)
  - oxycodone
  - hydromorphone
Neuropathic pain

A. Peripheral sensitisation

- Sodium channels
  - Carbamazepine
  - Lidocaine

- C- and Aδ-fibres

B. Central sensitisation

- Calcium channels
  - Pregabalin
  - Gabapentin

- 5-HT and NA
  - SNRIs
  - TCAs
Drugs used in treatment of neuropathic pain

- WHO step 2/3 analgesic
- + gabapentinoids – pregabalin 25mg nocte, gabapentin 100mg tds (act at calcium channels)
- or TCAs amitriptyline starting at 10–25mg nocte (stimulate descending inhibitory pathways)
- (carbamazepine – trigeminal neuralgia, sodium channels)
- Add NMDA receptor blocker Ketamine 0.1mg/kg subcut
Calcium channel function increases. Wind-up and long-term potentiation are induced. Brain facilitations up, inhibitions down.

Peripheral level: Altered ion channel function increases.

CNS level: Wind-up and long-term potentiation are induced. OPIOIDS block NMDA receptors.

Multi drug: GBP, PGB, Lidocaine, Lacosomide, CBZ, TCA duloxetine.
Guidelines pain management
Stepwise Healthcare Interventions for Pain (SHIP)

**NOCICEPTIVE PAIN**
- **STEP 1:** Mild pain
  - Paracetamol ± NSAID
- **STEP 2:** Moderate pain
  - Weak opioid or low dose morphine + STEP 1
- **STEP 3:** Severe pain
  - Strong opioid + STEP 1

**NEUROPATHIC PAIN**
- **STEP 1:** αδ-ligand or amitriptyline or SNRI
- **STEP 2:** Increase dose of step 1 drug, switch to an alternative step 1 drug or combination of step 1 drugs
- **STEP 3:** Switch to, or add tramadol or strong opioid; refer to specialist care

**NONPHARMACOLOGICAL INTERVENTIONS**
- Psychosocial interventions
- Physiotherapy
- Occupational therapy
- Intervential pain procedures

**ONCOLOGIC INTERVENTIONS**
- Radiation therapy
- Chemotherapy
- Surgery

(Complementary interventions: massage, aroma therapy, acupuncture, TENS, reflexology)

**BASELINE MANAGEMENT:** Assess, use effective communication and educate the patient

1. Pain assessment (nociceptive, neuropathic or mixed pain?):
   - Minimum pain assessment should include PQRST and DN4 (if neuropathic pain is suspected)

2. Ask about current treatments for pain (type, dose, frequency of administration):
   - Optimise dosing or discontinue as appropriate

3. Communication, counselling and patient education

**Regular reassessment**
Importance of clinical care in the terminal stage of the illness

To the patient

- Physical comfort in the face of challenging symptoms
- Dignity in death
- Emotional and spiritual support
- Non abandonment – ‘journeying with the patient’
Importance of clinical care in the terminal stage of the illness

- To family members
  - Impact on bereavement

- To the HCP
  - Change from attitude of “there is nothing more I can do”
  - Active care, management of symptoms
  - Being present, making a difference
  - Personal & professional satisfaction contributes to positive resilience
Care of the dying patient

- Ensure physical comfort as far as possible
- Optimum symptom control
- Emotional support to patient and family
- Non-abandonment
Management of the dying patient

- Explanation to patient and family
- Symptom management
  - Rationalise medication and discontinue non-essential meds
  - Continue/institute medication for symptom control
  - Route of administration (syringe driver)
  - Food and fluids
- Psychosocial support
- Spiritual support
 Discussion

- Explore patient’s/families’ understanding
- Fears – explain unrealistic fears, discuss how to manage/mitigate for realistic fears
- Advance directives
- Resuscitation
- Unfinished business
End of life tasks

- Forgive me
- I forgive you
- I love you
- Thank you
- Goodbye

Byock, Alexander
Death is no more than passing from one room into another. But there is a difference for me, you know. Because in that other room I shall be able to see.

Helen Keller
Symptom control

- Rationalise medication
- Route of administration
- Anticipate problems
- Common symptoms
Syringe Driver

- Indicated: not taking oral meds – lowered level of consciousness, dysphagia, intractable vomiting
- Meds used in SD
  - Morphine sulphate
  - Metoclopramide
  - Haloperidol
  - Midazolam
  - Hyoscine butylbromide
Support

- Patient
- Family caregivers
- Professional caregivers
Psychosocial support

- Pre-bereavement grief counseling
- Emotional and practical support of the family
- Respect of confidentiality
- Assisting the patient and family to come to terms with changing abilities, body image, roles
Specific Issues for HIV patients

- Younger patients
- Stigma and rejection
- Impact on support system
- Other family members affected
- Multiple losses/bereavements
- Previous experience – witness patients dying in distressing circumstances
Legal issues

- Advance Directive/Living Will
- Power of attorney
- Legal Will
- Next of kin/Guardianship of children
- Planning future care of potential orphans
- Funeral arrangements
- Death certificates.
Family support

- Face prognostic uncertainty
- Emotional strain
- Distress of watching deteriorating condition of the patient
- Require reassurance that they are doing a good job of caring for loved one
- Adjust to alteration of role eg husband to nurse
Demands on family

- Physical demands of nursing the patient
- Additional household tasks
- Interrupted sleep
- Emotional burden of care.
Family Needs

- Families need to be with dying patient
- Need to care for patient themselves
- Need information about the illness, impending death and what to expect,
- Need to express emotions and to receive comfort
Spirituality

“Man is not destroyed by suffering but by suffering without meaning”
Frankl

Search for meaning
Some patients are well supported within their own religious framework
FICA spiritual assessment tool

- Faith or belief
- Importance/Influence
- Community
- Assist

Puchalski
In caring for patients with life-threatening illness, there are often complex decisions to be made.

It is helpful to have a good understanding of bioethical principles to assist decision-making.

Patients and family members are often emotionally vulnerable and anxious; and confused by and fearful of unfamiliar information and setting.
The four principles of bioethics described by Beauchamp & Childress are helpful in clinical decision-making: autonomy, beneficence, non-maleficence, justice.

The South African Health Professions Council has clear general ethical guidelines for the health care professions to assist this understanding.
These principles may fail to take into account the individual and family members, personal preferences and context.

In palliative care and any end-of-life care setting it is important to consider each patient individually.
...Concerns

- Develop a care plan relevant to the individual, the stage of the illness, the person’s preferences and the family’s wishes.
- If shared decisions are discussed in an understanding and compassionate way we are more likely to achieve appropriate patient care with patient and family involvement in this care.
Bio-ethical principles...

- Autonomy – ‘self-rule’ the ability to make decisions for oneself based on deliberation; the decision maker has the required information, capacity and circumstances to make rational decisions.
- Beneficence provides benefit to the patient and balances the benefits against risks and costs; HCPs must keep up with modern medical knowledge, which includes knowledge and understanding of palliative care.
Non-maleficence: ‘do no harm’; any treatment should be provided with the intent to benefit the patient; do not embark on futile treatment that is unlikely to benefit the patient

Justice:
- distributive justice (fair allocation of resources),
- rights-based justice (similar to autonomy) eg fair access for the individual to health care
- legal justice according to the laws of the country
Next steps

Consensus statement – 17 national health departments at APCA/HPCA conference:

1. development of policy frameworks that strengthen health systems, by the integration of palliative care into hospital and community home-based care health services
2. integration of palliative care services into national health budgets
3. to ensure availability of, and access to, essential medicines and technologies
4. integration of palliative care into the nursing, medical school and other relevant training curricula
5. sharing of palliative care best practices
6. development of partnerships across the continent between governments and other players in health
HPCA project Care & Support for Improved Patient Outcomes (CaSIPO)

- Partners FHI360, FPD, SA Partners (I–ACT)
- Objectives

1. *mainstreaming of Comprehensive Care and Support–Palliative Care (CCS–PC) in all national policies*

2. *integration of CCS–PC programming into Primary Health Care*

3. *access to a continuum of high quality CCS–PC services and reducing loss to follow-up*
Conclusion

- Integration of Palliative Care into health services, including HIV care enhances:
  - **Quality of life** and physical comfort for the patient
  - Emotional, psychosocial and spiritual support for patient and family members
  - Family support through the illness and in bereavement
  - Support for health care workers, professional job satisfaction, resilience
Thank you for your attention

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