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Why Palliative Care?

- Explore our understanding of Palliative Care
- Discuss end-of-life care
- Discuss symptom management
- Discuss continuum of care
- Palliative care is an integral part of every healthcare practitioner’s role
What is palliative care?

- Is it the care of the terminally ill?
- The impact of HAART – changing HIV from an life-threatening illness to a chronic condition
- UNAIDS: approx 2m AIDS related deaths in 2008
- 6.06% of the global HIV-infected population died during 2007, only 0.4% of presentations at the IAC addressed their care
International AIDS conference 2010

- Richard Harding: “attendees rightly celebrated the successes of antiretroviral therapy”
- UNAIDS: approx 2m AIDS related deaths in 2008
- “high and increasing mortality rates, and growing incidence of progressive malignancies”
- “highlight the need for universal access not only to ART but also to palliative and end of life care”
- All health care workers require the skills of palliative care
Mortality findings

• Brazil - impressive declines in HIV mortality but 121,346 patients died over the 10 year follow up of 382,012 patients (TUAC0102).

• Another Brazilian study - 13.5% of a paediatric cohort died over a three year period (TUAC0103).

• Among South African miners, mortality is beginning to rise again after dramatically falling with increasing ART access, and mortality was never reduced to its pre-HIV epidemic level (TUAC0104).

• Data from the USA among socially disadvantaged persons also showed that HIV mortality is beginning to rise again (TUAC0105).
What is palliative care?

- Is it the management of distressing symptoms such as pain?
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
### 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>
<td></td>
<td>• Fatigue: 33-79%</td>
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<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>
<td></td>
<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>
</tr>
<tr>
<td>Depression and sadness</td>
<td>43% depressed</td>
<td>40-54% depressed</td>
<td>63% depressed 43-82% sad</td>
<td>38-57% depressed 78% sad</td>
</tr>
<tr>
<td>Anxiety, stress and worry</td>
<td>--</td>
<td>36-40% anxious</td>
<td>63% anxious 51-86% worried</td>
<td>31-43% anxious 82% worried 34% with post-traumatic stress disorder 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

When to initiate palliative care?

Disease-oriented care

Supportive and Palliative Care

Bereavement care

Diagnosis

Death

WHO 1998
Complex care needs in HIV

- Symptom burden patients on HAART attending outpatient HIV clinics in London
  - 63% tiredness
  - 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
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

- **Step 1**: Non-opioid +/- adjuvants
- **Step 2**: Weak opioids +/- step1
- **Step 3**: Strong opioids +/- step1
Analgesics

- **Step 1** - Paracetamol/aspirin/NSAID
- **Step 2** - codeine
  - (paracetamol-codeine combinations)
  - Tramadol
- **Step 3** - morphine
  - mist morphine (4 hrly administration)
  - morphine tabs
  - morphine sulphate inj (sub-cut)
  - Fentanyl (patches)
Prescribing morphine

- Morphine is the most commonly used strong opioid analgesic
- Morphine should not be withheld from patients experiencing severe pain
- There is no upper limit to morphine dosage
- For cancer patients, the usual starting dose is 10-20mg 4hrly and this dose is titrated upwards depending on the patient’s analgesic requirements
- HIV patients respond well to lower doses of morphine 5mg 4hrly
Morphine safety

Bioavailability graph

Serum levels

Time

Therapeutic range

Sub-therapeutic

Toxic

IV

Oral (titrated)

csci
Side effects of morphine

- Temporary confusion, drowsiness
- Nausea &/or vomiting – co-prescribe an anti-emetic for 1 week
- Constipation – may be of benefit for patients experiencing diarrhoea
- Tolerance occurs to morphine side effects except constipation NB prescribe laxatives concomitantly with morphine
• morphine does NOT cause respiratory depression in therapeutic dosage
• Physiological addiction is not seen but caution should be used when prescribing for patients with pre-existing addiction
• People who have experienced addiction may require higher doses of analgesics because of the potentiation of cytochrome P450 system
• It is suggested inflammatory mediators block kappa-receptor which is receptor responsible for euphoric effect of drugs by addicts
Adjuvant analgesics

- Corticosteroids
  - Increased ICP, soft tissue infiltration, nerve compression
- Antidepressant medication \(\rightarrow\) neuropathic
- Anticonvulsant medication \(\rightarrow\) pain
- Bisphosphonates
  - Bone pain
Drugs used in treatment of neuropathic pain

- WHO step 2/3 analgesic
- + Antidepressants amitriptyline starting at 10-25mg nocte
- or Anticonvulsants, carbemazepine 100mg bd, gabapentin 100mg tds (stabilise nerve membrane)
- Possibly NSAID for 5-10 day trial
- Pyridoxine for toxic neuropathy
- Add NMDA receptor blocker Ketamine 0.1mg/kg subcut
What is Palliative Care?

- WHO definition of palliative care

- Palliative care is the relief of suffering

- Palliative care is a response to the needs of the individual person with life-threatening illness and to the families’ needs – patient-centred care
WHO Definition of Palliative Care

Palliative care is 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.

http://www.who.int/cancer/palliative/definition/en/
Palliative care

- ‘Quality of life’
- ‘Affirms life’
- ‘Helps patients live as actively as possible’
- ‘Will enhance quality of life, and may also positively influence the course of illness’
- ‘Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life’
- In the HIV context palliative care has a significant role to play in the restoration to health for people who are HIV positive
Outcomes of care & support for PLHA and families

- Enhanced understanding of HIV
- Improved health & well-being
- Fewer distressing symptoms
- More rapid response to intercurrent infections and other problems
- Better adherence when treatment support is provided in the homes


Photo Khanya Hospice, South Africa
Outcomes of care & support for PLHA and families

- Better support to the family
- A reduction in lost to follow up cases
- Fewer deaths
- Reduction of reported depression
- Reduction of stigma & discrimination
- Improved self esteem


Photo Khanya Hospice, South Africa
How do we achieve these outcomes?

- Integrate palliative care into HIV care
- Palliative care/hospice nurse at ARV clinics
- Continuum of care into patients homes
- SA hospices – 98% care is provided in the patient’s home
How do we achieve these outcomes?

- Multidisciplinary team – community careworker, prof nurse, social worker, doctor, pastoral worker
- Paediatric palliative care – Early Childhood Development
- Patient as part of the team – identify & address patient’s needs
Palliative care goals in HIV

- Integration of palliative care into HIV care promotes:
  - Restoration to health
  - Quality of life
  - Dignity in death
  - Support of family in bereavement
Thank you

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