

Issues faced in caring for people living with HIV

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Attitudes to palliative care

- Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness
- From the USA has come a perception that palliative care is only about care of the dying
- So it is a difficult task to promote palliative care as society and esp the medical profession avoids talking about death

Steve Jobs...

- Remembering that I'll be dead soon is the most important tool I've ever encountered to help me make the big choices in life. Because almost everything - all external expectations, all pride, all fear of embarrassment or failure - these things just fall away in the face of death, leaving only what is truly important. Remembering that you are going to die is the best way I know to avoid the trap of thinking you have something to lose. You are already naked. There is no reason not to follow your heart.

...Steve Jobs

- Your time is limited, so don't waste it living someone else's life. Don't be trapped by dogma - which is living with the results of other people's thinking. Don't let the noise of others' opinions drown out your own inner voice.
- Your work is going to fill a large part of your life, and the only way to be truly satisfied is to do what you believe is great work. And the only way to do great work is to love what you do. If you haven't found it yet, keep looking. Don't settle. As with all matters of the heart, you'll know when you find it. And, like any great relationship, it just gets better and better as the years roll on. So keep looking until you find it. Don't settle

The essence of Palliative Care

- In essence, palliative care is a response to suffering; in particular a response to the needs of people living with life-threatening illness
- In responding to the needs of people with chronic illness, palliative care has adapted to assist people with chronic illness and different disease trajectories than advanced cancer

Palliative care & HIV

- Palliative care response in HIV depends on the availability of ARVs
- Imperative to advocate for access to HAART which is the most effective palliation for HIV
- Urgency to address prevention of infection

Palliative care in the developing world



↑
Diagnosis

↑
Death

← Hospice care →

← Primary Health Care & Specialist care →

Adapted from WHO
Defilippi, Gwyther 2002

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Palliative care & prevention of HIV infection

- Use of powerful teaching moments during the care of the terminally ill pain to promote prevention messages
- Prevention of infection through family and community awareness
- Promotion of and provision of voluntary counseling and testing programs
- Prevention of suffering
 - Early diagnosis and treatment OIs
 - Treatment of AIDS-related cancers (prevention, screening, early detection, treatment)
 - Management of distressing symptoms

Palliative Care & AntiRetroviral Treatment (hospices)

- Initiation of treatment for patients with very low CD₄ counts (less than 50) for the management of IRIS
- Treatment support to patients on ARVs based on comprehensive treatment literacy programmes
- Treatment of opportunistic infections and distressing symptoms such as pain, dyspnoea, nausea, diarrhea, skin conditions
- Treatment support for TB patients

Palliative Care in HIV

- Physical care – assessment and management of distressing symptoms for patients to improve quality of life
- Psychological and spiritual support to patients and family members through counseling, which may be individual counseling, family counseling, support groups, bereavement counseling, spiritual care

Expanding the scope of Palliative Care

- Hospices assist in poverty alleviation programs through income generation activities
- Hospices identify and support potential orphans and vulnerable children
- Hospices assist in developing food security through nutritional advice, food parcels, and support of community food gardens
- Hospices provide legal advice for patients – wills, succession planning, advocate for the right for access to palliative care (including marginalised groups – prisoners, refugees, sex workers)

Palliative Care at the end of life

- Hospice provide compassionate care of terminal patients ensuring physical comfort through control of distressing symptoms, which assists in promoting dignity for the dying patient; emotional support for the patient and family members and bereavement care.

Palliative Care at the end of life

- Hospices reach about 20% of patients who die from their progressive illness
- Palliative care must be integrated into health care services to ensure access to palliative care when this is needed

Palliative care in HIV

- Physical
 - Early diagnosis & management of OIs
 - Management of pain & other distressing symptoms
- Psychosocial
 - Young people
 - Previously wage earners, with children
 - Multiple bereavements
- Spiritual care

Psychological support

- Pre-bereavement grief
- Family support
- HIV -young patients, stigmatisation, other family members affected, confidentiality
- Body image
- The role of support groups
- Multiple losses/bereavements (memory work)

Social support

- ID book
- Loss of income – grant applications
- Cost of care
- Will, next of kin
- Planning future care of potential orphans
- Funeral arrangements

Spiritual support

- End of life issues
- Pastoral carer from own faith
- Respect for patient's faith
- The task at end of life is to make sense of, and find meaning within patient's on world view.

Case Studies

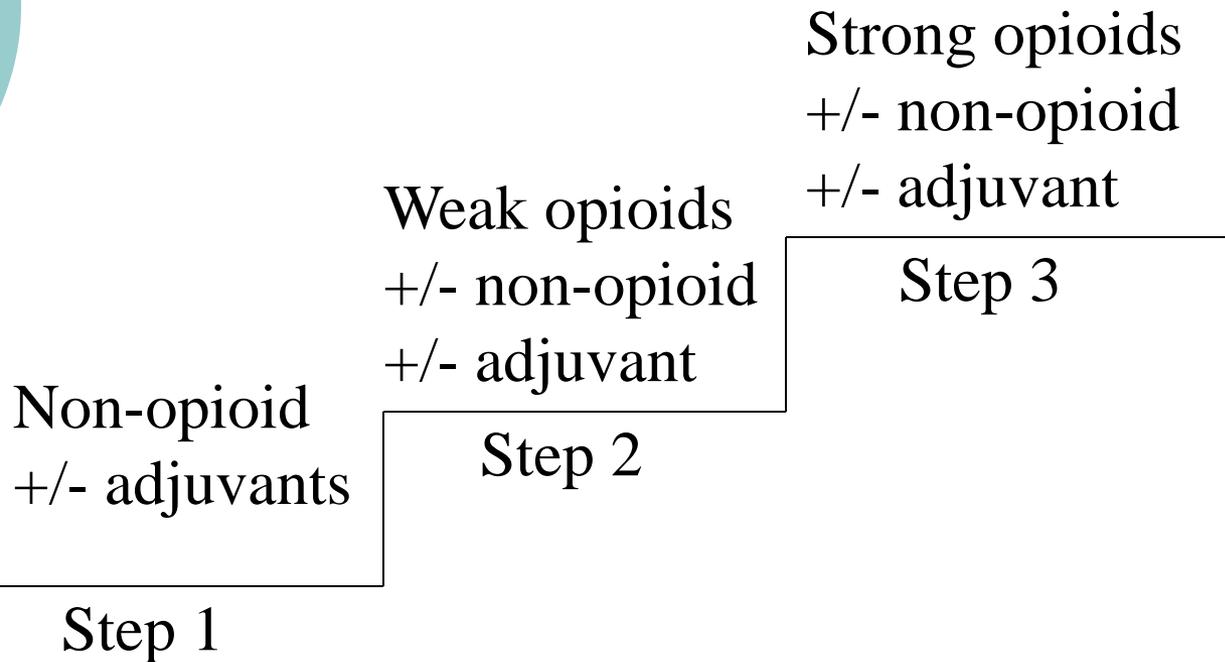
Prevalence of pain

- Cancer patients: 75% experience pain, of these 30% experience 3-4 different pains (ref Twycross)
- AIDS Patients: 97% of patients with stage 4 HIV experience pain; 7 different causes of pain (Ref Norval, Hardman)
- Requires 'impeccable assessment and treatment of pain'

Principles of Analgesic Use

- By the mouth
- By the clock
 - At regular intervals, most short-acting analgesics 4 hrly
 - No place for 'prn' analgesia
 - NB prescribe breakthrough dose
- By the ladder
- For the individual

WHO 3-step analgesic ladder



Analgesics

- Step 1 - Paracetamol
 - aspirin
- Step 2/3 - Tramadol
- Step 3 - morphine - mist morphine
 - morphine tabs
 - morphine sulphate inj
 - fentanyl (patches)

Adjuvant analgesics

- Non-steroidal anti-inflammatory drugs
 - Bone pain, soft tissue infiltration, hepatic capsule pain
- Corticosteroids
 - Increased ICP, soft tissue infiltration, nerve compression
- Antidepressant medication } neuropathic
- Anticonvulsant medication } pain
- Bisphosphonates
 - Bone pain

Using adjuvants in control of HIV neuropathic pain

- Mist morphine 5mg/4hrly (titrate to maximal tolerated dose)
- Amitriptyline 10mg nocte (increase every 2nd day by 25mg to 100mg if no effect stop and try carbamazepine or gabapentin)
- (Vitamin B_{co})

Caring for the carers

- Family carers
- Professional carers
- Adequate training
- Supervision
- Support
- Burn-out
- Positive resilience
- Support/improve morale

Palliative care – the continuum of care...

- Providing palliative care “in conjunction with other therapies that are implemented to prolong life” means that there is no **transition** to palliative care

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- All care should start with a patient-centred focus and the contribution of symptom control and comfort measures, including emotional and spiritual support becomes a larger part of the care
 - The decision then is are there therapies that should be withdrawn



Thank you

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Guidelines for Providing Palliative Care to Patients with Tuberculosis



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