1 ◻ # Palliative Care / Care & Support

for

HIV/AIDS

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2 ◻ # Objectives

- Importance of *continuum of care and support* in management of HIV/AIDS
- Identify challenges in caring for persons with HIV/AIDS

3 ◻ # Image of market

4 ◻ # What is the point?

- Are we measuring outcomes that actually mean something in the life of a PLWHA?
- Can care manipulated by competitive agencies be offered in a manner that provides a lifetime of quality time with family and friends?
- Who is to say what quality is from one day to the next for you? For me? For someone living with HIV?

5 ◻ # Estimated Incidence of AIDS and Deaths among Adults and Adolescents with AIDS, 1985-2002, United States

6 ◻ # POP Quiz:

- Of 10 people living with HIV disease:
  - 2 have progressive hepatitis C
  - 1 has substance-associated renal failure
  - 1 is on Maraviroc and a failing backbone
  - 1 has decompensated cardiac failure after years on HAART
  - 1 has miliary TB and not yet started on ART
  - 1 has disseminated Kaposi's sarcoma
  - 1 has Cryptococcal meningitis with a headache 7/10
  - 1 has recurrent panic attacks
  - 1 has lost 30# and his ability to talk

7 ◻ # Of those 10 people -

How many are going to die?

8 ◻ # Image of beach

9 ◻ # Focus shift

- From life of the virus to life of the host
- Goal = viral suppression + HRQoL

- Impact on family / community / self

10 ▣ Shift in Focus
- Understand care of patient within the context of life (trajectory of illness)
  – Care targeted to stage of illness
  – Role of family and community

11 ▣ Three intersecting circle: Community, Clinic, Patient; Staff appears at the intersection

12 ▣ Continuity of Care: Stages of Care and Support

13 ▣ Context of Care
- Care of the individual
  – Goals of Care and Health-Related Quality of Life
    - Clinical - impeccable attention to detail
- Continuity model of care over time
  – Importance of interdisciplinary team
  – Hospital / Clinic / Home
- Impact of care
  – On patients and families
  – On the bereaved and community
  – On ourselves

14 ▣ Meaning for patient with HIV/AIDS

15 ▣ Care Skill Set
- Communication skills
- Management of total pain & other symptoms including mental health issues
- End-of-Life issues - dying, grief & bereavement
- Care of care providers - ?Task-shifting
- Measuring & improving impact of care and support on patient, family and community

16 ▣ Under-lying motivation for use of palliative approach
- Attention to physical concerns often displaces time needed for essential elements that are then neglected
  – Physical pain vs psycho-spiritual issues
  – Concrete, daily needs vs end-of-life closure and effective grieving

17 ▣ Continuum of Care

18 ▣ Goals of PC
- Modify management based on prognosis

- Patient and 'family' as unit of care
- Provision of comfort measures
- End-of-Life closure
- Ethical / cultural / spiritual issues
- Grief and bereavement

19 ☐ Image of women carrying babies on their backs

20 ☐ Image of members of interdisciplinary Team: Doctor, Assistant, Pharmacist, Adherence Officer/CO, Volunteer

21 ☐ Symptoms experienced at all stages

22 ☐ Pain
- Importance as a representative symptom
- Prevalence and impact
- Approach to assessment and treatment
- Need for advocacy for opioids
- May not be a relevant topic in resource-constrained settings

23 ☐ *TOTAL PAIN*

24 ☐ Palliative Care for

HIV/AIDS and/or Cancer (2001-2003)
- Less than 1% can access ARV's
- Less than 5% of cancers reach chemotherapy or radiotherapy
- 40% of Africans never see a   health worker
- Research in Sub-Saharan Africa   by WHO in these countries shows   preference for dying in own homes

Influenced by effects of Government regulations on finances.

25 ☐ Relative Barriers to Discussing and Improving End-of-Life Care
- Individual discomfort in dealing with issues related to end-of-life – *all countries / cultures*

- Lack of acknowledgment of importance results in not knowing what to do / *withdrawing*

- Resulting in
  - **Critical conversations are introduced too late**
  - **Families are left alone to cope with dying**
  - **Exaggerated risk of over-medicalization and unrealistic attempts to prolong life**

26 ☐ Image of list of names; Multiple Loss in Families

27 ☐ Specific problems in HIV/AIDS that interfere with effective support
- Stigma

- Cultural issues
- Young people dying
- Displaced populations
- Others?

28 🔲 Causes of death

in inner city population [63/132 (48%)]

- AIDS (38%)
- Sepsis (19%)
- Cancer (19%)
- Liver failure/cirrhosis (17%)
- Other (7%)

- Death predictable by functional status alone not usual disease markers: e.g. CD4 or VL

29 🔲 Image of gravesite; Impact of Multiple Losses can not be under-estimated

30 🔲 Image of children in Africa; Orphans are the Bereaved in Many African Countries

31 🔲 Methods for Supporting Staff
- Basic team building exercises –
  - Fun and foster unity
  - Build on competitive spirit
  - Highlight creativity
- Use of humor
- Recognition and rewards
- Beautification of space – keep it simple!

32 🔲 Image of eagle sitting in treetop

33 🔲 We each need a source of inspiration. .
- A child / children
- Pets
- Community work
- Spiritual beliefs
- Beauty of nature
- Time alone
- Singing / reading / watching a movie

34 🔲 What gives you strength?

How often in a week do you go to this source?

35 🔲 Image of tree

36 ▣ Maker of Dreams Reflection

As we bring healing . . .
Not to forget
To remind us that the answers to life are within each of us
Our role is to accompany on the journey

37 ▣ Life is a journey

- We are the accompanionteurs
  - For patients and their families
  - For our own families
  - For other staff members
  - For friends in our community

38 ▣ Intention, Love, Belief, Compassion, Faith, Charity, Imagination, Strength, Presence, Hope, Creativity

39 ▣ Faith

Is knowing that when you step into darkness of the unknown. . .

You will land on something solid. . .

or you will be taught to fly

40 ▣ Asante Sana, Zikomo, Merci Bien, Thanks

41 ▣ Image of sunset

42 ▣ Reading

- Sepulveda C, et al *Brit Med J* 2003
  327:209-213 (Quality Care @ EOL in Africa)
- Harding R and Higginson I *Lancet* 2005
  365(9475):1971-1977 (PC in SS Africa)
- Makoae LN et al (Holzemer) *JANAC* 2005
  16(3):22-32 (Sx experience PLWH/A Southern Africa)
- Alexander, C in Anderson, J ed *A Guide to the Clinical Care of Women with HIV Disease*, HRSA 2000
- Bond, Lavy and Wooldridge Palliative Care Toolkit, Worldwide Palliative Care Alliance, 2008

43 ▣ Palliative Care on the Internet

- **http://www.growthhouse.org** collection of resources on palliative care
- **http://www.symptomcontrol.com** addresses individual symptoms
- **http://www.chcr.brown.edu/pcoc/Toolkit.htm**   a collection of tested instruments for measuring end-of-life care concepts
- **http://www.eperc.mcw.edu** *Fast Facts* (Project of Palliative Care Center, Medical College of Wisconsin) 1-2 page summaries addressing all topics
- **http://ww.epec.net** Educating Physicians about End-of-life Care developed by American Medical Association (provides bulk of under-lying information used in the African Palliative Care Association curriculum) www.apca.org
- King's College London – Post-doctoral degree in Palliative Medicine **http://ww.kcl.ac.uk/** Other programs now exist at University of Cape Town

and Nairobi Hospice. All are distance-based requiring only short time periods in the respective countries; King's College is more advanced in terms of developing and pursing research.