1 Palliative Care / Care & Support for HIV/AIDS

Carla S Alexander, MD, FAAHPM
Assistant Professor of Medicine
Director Palliative Care and Support

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 underestimated

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
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

Life is a journey
• We are the accompanioniteurs
  – For patients and their families
  – For our own families
  – For other staff members
  – For friends in our community

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

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

Asante Sana, Zikomo, Merci Bien, Thanks

Image of sunset

Reading
  327:209-213 (Quality Care @ EOL in Africa)
• Harding R and Higginson I Lancet 2005
  365(9475):1971-1977 (PC in SS Africa)
• Makoea 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

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.eperec.mcw.edu Fast Facts (Project of Palliative Care Center, Medical College of Wisconsin) 1-2 page summaries addressing all topics
• http://ww.eperec.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 pursuing research.