Key Points

1. Protease inhibitors are used widely in both newly infected and established patients.

2. HIV/AIDS is now considered a chronic illness such as diabetes mellitus or hypertension.

3. Physical suffering in HIV/AIDS may come from opportunistic infection, malignancy, treatment toxicity, or organ failure.
   Opportunistic infections may develop when immune competency cannot be restored due to disease resistance, patient noncompliance, or lack of availability of treatment. Opportunistic infections—which include MAC, CMV, toxoplasmosis, and wasting—may lead to death within 12 months of onset.

4. Complications may develop when immune competency cannot be restored.
   Complications include progressive multifocal leukoencephalopathy; dementia; and cancers such as B cell lymphoma, primary CNS lymphoma, and cervical cancer in women. Complications may lead to death within 12 months of onset.

5. Complications may develop from treatment.
   Complications of treatment may include diabetes mellitus, pancreatitis, lipid dystrophy with stroke or heart disease, hepatic injury, or bone marrow suppression.

6. Other complications or organ failures may develop.

Key Points

1. HIV/AIDS often involves significant emotional suffering.
   Emotional suffering of HIV/AIDS hospice patients may include depression and suicidality, cognitive impairment, substance abuse, anxiety, mental illness and homelessness, and issues of gender and sexuality.

2. HIV/AIDS often involves significant social suffering.
   Social suffering of HIV/AIDS hospice patients may be related to relative youth of infected persons; infection of multiple members of family or community group; estrangement from family and/or society; loss of income and lack of insurance; unstable living environment; loneliness and dissatisfaction with available support; lack of recognized long-term relationship; need for advance care planning; and need for residential care.

3. HIV/AIDS often involves significant spiritual suffering.
   Spiritual suffering of HIV/AIDS hospice patients may be related to perceived and/or actual discrimination secondary to sexual expression, race, ethnicity and/or class; perceived and/or actual rejection by faith community; fear of divine judgment and retribution; lack of time to process life events and develop sources of meaning and transcendence; and unmet need for grace and mercy.

4. Persons with HIV/AIDS frequently receive care at Life's End in "nontraditional" hospice settings such as acute care hospitals, residential care facilities, and prisons.
   Late hospice referrals are frequent for persons with HIV/AIDS due to patients' hesitation to accept hospice care, providers' difficulty determining appropriateness because of effectiveness of HAART treatment, and absence of stable home environment and primary caregiver.
   New service models incorporating coordinated and holistic interdisciplinary care may be especially important in treating persons with HIV/AIDS, who have met with fear, prejudice, and discrimination in the healthcare system.

5. Palliative care for persons with HIV/AIDS could become a model for incorporation of palliative care into treatment of other chronic illnesses.

The Palliative Response

Changing Natural History of HIV/AIDS

Early 1980s
Clusters of PCP Pneumonia

- Identification of high-risk groups in US
  - *Gay men*
  - *Injecting drug users*
  - *Hemophiliacs*

Changing Natural History of HIV/AIDS

Mid 1980s
Identification of HIV as the causative agent

- Screening and testing of at-risk groups
- Identification of the routes of infection
- Development of education/ prevention campaigns
- Mounting numbers of deaths from AIDS

Changing Natural History of HIV/AIDS

Mid 1980s
Understanding of the natural history of infection

- Acute infection (usually not recognized)
- Long asymptotic (infectious) period
- ARC (AIDS related complex)
- Opportunistic infection and/or certain types of cancers leading to death

Changing Natural History of HIV/AIDS

Mid 1980s
Understanding of the natural history of infection

- Lose about 100 CD4s/year
- Relationship to CD4 lymphocyte depletion

500–1000/dl	*Normal*
200–500/dl	*ARC*
<200/dl	*PCP*
<100/dl	*Other opportunistic infections (OI) and death*

Changing Natural History of HIV/AIDS

Late 1980s
Treatment

- TMP/Sulfa for PCP
- AZT trial
- DDI trial
- People living longer develop other opportunistic infections
  - *Cytomegalovirus (CMV)*
  - *Mycobacterium Avium Complet (MAC)*

Changing Natural History
of HIV/AIDS

Early 1990s
Recognition that the medicines developed could be toxic and lose effectiveness

- Development of other NRTIs
- Development of NNRTIs
- HIV/AIDS hospice programs in larger cities (San Francisco, New York, Chicago)

Changing Natural History
of HIV/AIDS

Early 1990s

- Beginning to appreciate the crisis developing in Sub-Saharan Africa, Asia, and other developing countries
- Hospice programs in smaller communities begin to have more referrals as local infection occurs and persons living with AIDS (PWA) return to live with their families

Changing Natural History
of HIV/AIDS

Early 1990s
Finding expression for the crisis

- AIDS Quilt
- Red Ribbons
- *Angels in America* (play)
- *RENT* (musical)
- *The Band Played On* (book and movie)
- *Philadelphia* (movie)

Changing Natural History
of HIV/AIDS

Early 1990s
New treatments

- PI Protease Inhibitors introduced
- HAART (Highly Active Anti-Retroviral Therapy) 2NRTIs and a PI
- People with AIDS on their death beds got up and walked out of hospices
- Irrational exuberance (possible cure)

Changing Natural History
of HIV/AIDS

Late 1990s to present

- PI Protease Inhibitors widely used in both newly infected and established patients
- HIV/AID specialty hospice programs close
- New side effects and toxicity identified
- Cost of treatment > $1000/month
- Patients begin to fail treatment because of the development of resistance

Changing Natural History
of HIV/AIDS

Late 1990s to present:
Infection escalates
in developing countries

- HIV/AIDS infection rate in some South African countries reaches 25% of the population
- Protest about the inability to afford or access treatment in developing countries
- Development of HIV/AIDS hospice care in developing world

Changing Natural History
of HIV/AIDS

Late 1990s to present

- View HIV/AIDS in USA as chronic illness such as DM or HTN
- Hospice referral of patients with HIV/AIDS resumes
- The future

The Experience of Dying from HIV/AIDS

Social

Physical

Suffering

Emotional

Spiritual

Palliative Care

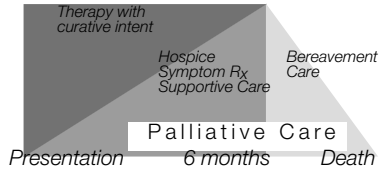
"Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure…

Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs…

It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."

Institute of Medicine 1998

Palliative Care



Physical Suffering

- Opportunistic infection (OI)
- Malignancy
- Treatment toxicity
- Organ failure

Physical Suffering
Opportunistic Infection

Opportunistic infection may develop when immune competency cannot be restored due to:

- Lack of response (resistance)
- Noncompliance with treatment
- Lack of availability of treatment (developing countries)

Physical Suffering
Opportunistic Infection

Complications when immune-competency cannot be restored may lead to death within 12 months of onset

- MAC 74%
- CMV 70%
- Toxoplasmosis 73%
- CMV and MAC 99%
- CMV and wasting 88%

Physical Suffering
Complications

Complications when immune-competency cannot be restored may lead to death within 12 months of onset

- Progressive multifocal leukoencephalopathy 100%
- Dementia 79%
- Cancers such as B cell lymphoma, primary CNS lymphoma, and cervical cancer in women

Physical Suffering
Complications of Treatment

- Diabetes mellitus
- Pancreatitis
- Lipid dystrophy with stroke or heart disease
- Hepatic injury
- Bone marrow suppression

Physical Suffering
Complications and Organ Failures

- Renal failure
- Liver failure with Hepatitis B and/or C
- Cardiomyopathy
- Co-morbid risk of injury from drug and alcohol abuse

Palliative Care and Hospice Referrals

Indications for referral

- HAART therapy ineffective
- HAART therapy not tolerated well
- PWA declines treatment for HIV
- Complications such as dementia, PML
- HIV may be secondary diagnosis with the primary diagnosis being hepatic failure, cancer, etc.

Palliative and Hospice Care

- Physical symptoms may be similar to those of other patients referred to hospice although may have larger number
- Special issues

  Pain control in patients with history of past or current drug use

  Decisions about continuing some OI or HIV treatments

  Management of specific OI/HIV problems in concert with HIV specialist

Emotional Suffering
and HIV/AIDS

- Depression and suicide
- Cognitive impairment
  Dementia or PML
- Substance abuse
- Anxiety
- Mental illness and homelessness
- Sexuality issues

Social Suffering
and HIV/AIDS

- Relative youth of infected individuals
- Infection of multiple members of family or community group
- Estrangement from family and society
- Loss of income
- Lack of insurance—Medicaid and Medicare issues

Social Suffering
and HIV/AIDS

- Unstable living environment
- Loneliness
- Dissatisfaction with available support
- Lack of recognized long-term relationship
- Need for Advance Care Planning
- Need for residential care

Social Suffering
and HIV/AIDS

Perceived and actual discrimination

- Sexual expression
- Race
- Ethnicity
- Class

Spiritual Suffering
and HIV/AIDS

- Perceived and actual rejection by faith community
- Fear of divine judgment and retribution
- Lack of time to process life events and develop sources of meaning and transcendence
- Unmet need for grace and mercy

Palliative Care
for HIV/AIDS

- Many HIV/AIDS primary care providers have recognized the importance of incorporating nursing, social work, pastoral care, and mental health in a coordinated holistic model of care
- New service models have developed because of fear, prejudice, and discrimination by community providers

Hospice Care
for HIV/AIDS

Late hospice referrals are common

- Difficult for patients to accept hospice
- Difficult for providers to determine appropriateness because of effectiveness of HAART treatment
- Lack of stable home environment and primary caregiver

Hospice Care
for HIV/AIDS

Persons with HIV/AIDS frequently receive EOL care in "nontraditional" hospice settings

- Acute care hospitals
- Residential care facilities
- Prisons

Hospice Care
for HIV/AIDS

- There is an international need for hospice and palliative care as primary treatment because of lack of infrastructure for medical treatment
- HAART is unlikely to become widely available because of expense and difficulty of treatment management in poor and developing countries

Palliative Care
for HIV/AIDS

- Needs to be available to patients and their medical providers
- Could become a model for the incorporation of palliative care into other chronic illnesses
- Care needs to be flexible and responsive to patient and caregiver needs
- Providers need to learn from each other about management of HIV/AIDS throughout the course of the disease

Palliative Care
for HIV/AIDS

Offers possibility for growth

- Individual
- Community
- Profession

HIV/AIDS
and Palliative Care

Consult early and often.

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