ART, Palliative Care & Hope

Anne Hughes, ACRN, ACHPN, PhD, FAAN

Advanced Practice Nurse, Palliative Care
Laguna Honda Hospital and Rehabilitation Center/SFDPH
25th ANAC Annual Conference
Tucson, AZ, November, 2012

Background

- Thirty years ago, HIV/AIDS was a death sentence few escaped.
- In the ‘early days’ HIV/AIDS nursing care focused on symptom management, psychosocial support, advocacy, and end of life care.
  - In 1980-90s, many persons with AIDS, estranged from family, appointed a surrogate decision-maker, (aka health care agent, proxy, or durable power of attorney) to ensure their wishes and values guided care decisions.

Overview

- Background
- Purpose
- Review of the literature
- Selected findings from research
- Case study
- Clinical implications

Background (cont.)

- Today, persons living with HIV (PLWHA) who receive ART early in the disease course, have a life expectancy almost comparable to those who are uninfected (Fauci, Folkers, 2012).
- Conversations about ‘why if …’ OR ‘what matters most to you if you became sicker ’ … are postponed
  - until repeated hospitalizations or evidence of disease progression,
  - and, not unlike others without HIV.
**Purpose**

To identify challenges & opportunities for incorporating palliative care into HIV/AIDS treatment paradigm.

---

**Review of the Literature**

- Little clinical or research literature was located, in nursing or medicine in the U.S., discussing HIV/AIDS and palliative care.
- Indeed, ANAC’s Core Curriculum, 3rd edition, included the term in one page discussing assisted suicide.

---

**Epidemiology of Aging and Dying among Persons with HIV/AIDS**

- 15% of all new HIV/AIDS diagnoses
- 24% of all PLWA (up from 17% in 2001)
- 19% of all AIDS diagnoses
- 29% of all persons living with AIDS
- 35% of all deaths in persons with AIDS
- By 2015, some estimates are that 50% of all persons with HIV will be > 50 years
  (Source: CDC, HIV/AIDS Among Persons Aged 50 and Older)
**Changing HIV Trajectory** (Fausto, Selwyn, 2011)

- 1981-1991 **OI/Terminal Illness Era**
  - Most deaths were due to untreatable/untreated OIs
- 1991-2001 **ART/Medicalization Era** (case definition ▲)
  - Cases increased; deaths decreased with OI prophylaxis & ART viral suppression and immune reconstitution
- 2001- now **Chronic Illness Era**
  - Morbidity & mortality linked to co-infection with Hep C, DM, lipid disorders, CVD, cancers, debility and other end organ diseases

---

**Chronic Illness Era – ART Guidelines**

- HHS ART guidelines (March 2012) note that there is little RCT data about benefits and risk of ART in older patients to guide decision-making, although virologic and immunologic improvement has been observed. Immunologic response is likely to be less robust a response than what is seen in younger adults.
- The prevalence of co-morbidities medications necessary to treat other chronic diseases in older adults, increase risk of possible drug-drug interactions.
- Discontinuation of ART is not recommended because of the possibility of viral rebound, immune decompensation and clinical progression.


---

**ART Guidelines for Older Patients with HIV**

"Few data exist on the use of ART in severely debilitated patients with chronic, severe, or non-AIDS terminal conditions. Abrupt withdrawal of ART usually results in rebound viremia or a decline in CD4 cell count... In very debilitated patients, if there are no significant adverse reactions to ART, most clinicians would continue therapy. In cases where ART negatively affects quality of life, the decision to continue therapy should be made together with the patient and/or family members after discussion on the risks and benefits of continuing or withdrawing ART, pp I-30."

---

**Poor Prognostic Indicators** (Fausto, Selwyn, 2011)

- Functional status: ADL impairments
- > 65 years of age
- IDU as HIV exposure risk
- Prolonged CD4 nadir and virologic failure
- Diarrhea > 1 month
- Advanced liver disease
- PML
- Burkitt’s Lymphoma
- Primary CNS Lymphoma
- Other malignancies
Twenty four (24) month survival rates in selected non-AIDS cancers (Fausto, Selwyn, 2011)

<table>
<thead>
<tr>
<th>Type</th>
<th>Pre-ART</th>
<th>Post –ART</th>
<th>Without HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>5%</td>
<td>10%</td>
<td>31%</td>
</tr>
<tr>
<td>Laryngeal</td>
<td>63%</td>
<td>31%</td>
<td>70%</td>
</tr>
<tr>
<td>Colorectal</td>
<td>9%</td>
<td>63%</td>
<td>73%</td>
</tr>
<tr>
<td>Hodgkins</td>
<td>19%</td>
<td>55%</td>
<td>89%</td>
</tr>
<tr>
<td>Prostate</td>
<td>44%</td>
<td>67%</td>
<td>95%</td>
</tr>
<tr>
<td>Sq Cell Anus</td>
<td>32%</td>
<td>76%</td>
<td>78%</td>
</tr>
</tbody>
</table>

Hope

- Hope has been recognized as important in how persons cope with the everyday travails of life, and with chronic and life limiting illness.
- As the HIV treatment paradigm has shifted with ART as standard of care, understanding the dynamics of hope along the spectrum of HIV disease is important to support psychosocial wellbeing.
- Kylma (2001) and colleagues interviewed 10 Finnish adults to describe the dynamics of hope while living with HIV/AIDS using grounded theory.

Dynamics of Hope in PLWHA (Kylma, et al. 2001)

- Participants described a dynamic of alternating among hope, despair and hopelessness.
- Themes that represented this balance were:
  - “Believing life to be worth living at the present and in the future.” (hope)
  - “Losing one’s grip and sinking into narrowing existence vs. fighting the sinking” (despair)
  - “Giving up in the face of belief of nonexisting future.” (hopelessness)
- The balance among hope, despair and hopelessness took place in the context of experiences that allowed unfolding or opening of possibilities
  - e.g., constructive life experiences or relationships, finding meaning in life, caring, able to control one’s life, improving health, being alive,
- and experiences that folded or shut down possibilities
  - i.e., fear, uncertainty, care problems, negative attitudes/stigma, loss and difficult relationships.

Selected Qualitative Research Findings from Study of Persons with Advanced HIV Disease in Residential Setting Post ART
What do you hope for?
- ... to be understood by another human being.
- ... to stay out of jail and (able to keep life together)
- ...to keep faith and hope alive (aspirational)
- ...to receive the (nursing) care I need
- ...that my children will understand my need to care for myself
- ...to keep living

ART protection from death
“A lot of people think because you’re taking that medicine, like, “Oh good, it’s okay.” And no it isn’t. Like- it’s like life or death, you know? And if you slip up, you know what I mean? And stop taking those little pills, you will die. (his emphasis) I don’t care what you think, you will die. And that’s the only thing that keeps you alive. So like I get up in the morning, take those pills. I do whatever they tell me to do whether I don’t feel like I want to. I just do it. And if I get out, I’m gonna continue doing it. ‘Cause I’ve seen too many people be healthy, go out, come back. Next thing you know, they’re dead…. I’m serious.” Willy, 50+ AA man receiving care in residential HIV/AIDS setting.

Living & dying from HIV as a choice
“Mary Ellen: I think something that everybody goes through when they first come here is they have to make a choice, you know… “Am I gonna live or die?” And I literally see people make the choice to die.
Anne: You’ve seen that, too?
Matthew: Yeah… you wanna fight for your life ‘cause you wanna live. You’re gonna fight it and do whatever it takes to get well. And some people just give up. They just lay there.
Mary Ellen: They lay in their bed. They stop taking their meds. And the next thing you know, they’re gone...
Mary Ellen: And they don’t see that they’ve gotta make a choice and they’ve gotta take care of them (selves). You know?”
(Mary Ellen, 50+ multiracial woman with AIDS and Matthew 30 something AA man with HIV)

HRSA HIV/AIDS Palliative Care Definition:
- Palliative care is patient- and family-centered care… optimizes quality of life by active anticipation, prevention, and treatment of suffering.
- …emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs.
- Palliative care facilitates patient autonomy, access to information, and choice.
(Excerpted from: HRSA Working Group on HIV and Palliative Care Palliative and Supportive Care. HRSA Care ACTION, July 2000)
Symptom Management

- Fatigue/weakness
- Weight loss/anorexia
- Fevers/sweats
- Pain
  - Nociceptive
  - Somatic
  - Visceral
  - Neuropathic
- Nausea/vomiting
- Diarrhea
- Constipation

http://hab.hrsa.gov/deliverhivaidscare/clinicalguide11/cg-405_palliative_care.html#t-1

Advance Care Planning, Aging & HIV
(Erlandson et al 2012)

- Cross-sectional study completed in outpatient clinic in academic medical center
- Subjects were 45-65 years; on ART at least 6 months with virologic response
- Results
  - 47% completed ACP
  - Persons more likely to complete ACP were:
    - Male, > 55 yrs old, higher income and education, MSM, living with partner, roommate or others, reported poorer health related QOL
  - Clinical conditions associated with ACP completion were cardiac event, disability or frailty

Advance care planning/Goals of Care

- Appreciating the values that shape what matters to this person.
- Initiating this discussion at time of diagnosis while also instilling ‘hope’, as well as times of transition.
- Mechanisms for documenting wishes: advance directives, POLST/MOLST
- Considering how to discuss escalating or not escalating medical interventions, or discontinuing non-beneficial therapies.
- Responding to requests for aid-in-dying if terminally ill.
Clinical Implications

- Symptom management is critical to expert HIV/AIDS care and to palliative care.
- In the absence of cure, HIV/AIDS care is palliative.
- Clients/patients with long-term therapeutic relationships with primary care providers/case managers are best served when their hopes, concerns for care as illness progresses explored before medical crises when introduced by ‘strangers in hospital or emergency room.’

Conclusion

- In the three decades since HIV was 1st recognized, treatment has transformed HIV into a chronic illness.
- Nevertheless, disease progression and death still occur, thankfully, not at the overwhelming, heartbreaking rates as seen in the beginning.
- Palliative care offers a means of holistically engaging clients and their families in care that enhances quality of life, offers a path to navigate changing health and treatment demands, while providing meaning and hope.

References

- Centers for Disease Control and Prevention: http://www.cdc.gov/hiv/topics/surveillance/resources/slides/general/index.htm
o Panel on Antiretroviral Guidelines for Adults and Adolescents.


**Thank you**

Anne Hughes, ACRN, ACHPN, PhD
Advanced Practice Nurse, Palliative Care, Laguna Honda Hospital/SFDPH
Anne.hughes@sfdph.org
Tel. 415.759.4569