Cultural Competency in the Population Aging with HIV: An Overview

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Objectives

• Develop tools clinicians need to care for culturally diverse elderly
• Review the epidemiology of the aging population of HIV+ adults in the United States
• Discuss common co-morbidities in aging patients with HIV
• Understand the management of aging patients with HIV
Our patients are living longer...

- Dramatic success of antiretrovirals has lengthened the lifespan of patients with HIV
- Patients no longer dying of opportunistic infections
FIGURE. Estimated number of AIDS diagnoses and deaths and estimated number of persons living with AIDS diagnosis* and living with diagnosed or undiagnosed HIV infection† among persons aged ≥13 years — United States, 1981–2008

Abbreviations: AIDS = acquired immunodeficiency syndrome; HIV = human immunodeficiency virus.
* Yearly AIDS estimates were obtained by statistically adjusting national surveillance data reported through June 2010 for reporting delays, but not for incomplete reporting.
† HIV prevalence estimates were based on national HIV surveillance data reported through June 2010 using extended back-calculation.
Prognosis of HIV in 2015

- Data from a Swiss cohort demonstrated that HIV+ patients with CD4 >500 cells/μL on HAART have same mortality rate as general population.

- Life expectancy for HIV+ patients in the United States approximately 43 years if diagnosed at age 20 (2/3 lifespan of HIV- population)
Causes of Death in Patients with HIV

Overall deaths versus HIV-related and non-HIV-related deaths from 1999 to 2004. The rates per 10,000 persons with AIDS are shown for each year.
Epidemiology of Aging with HIV in the United States

- Patients greater than 50 years of age account for:
  - 17% of new infections/year
  - 24% of AIDS diagnoses
2015

- Estimated that >50% of patients in the United States with HIV are >50 years
Age Distribution of HIV+ Patients in the US

Estimated Number of Persons Living with HIV/AIDS

2003
2006
Culture and Medical Care
Culture: Definitions

- The behaviors and beliefs characteristic of a particular social, ethnic, or age group
- The sum total of ways of living built up by a group of human beings, including behavioral norms, language, communication style, patterns of thinking, beliefs and values
Determinants of Culture

• Defined by:
  • Grouping/setting
    • Ethnic, racial, religious, corporate, professional, age, socioeconomic status, sexual orientation
  • Self-identification
  • Stereotyping by others
“Active Culture”

• Developed by Gupta
• Though we share a general culture with other people, each of us has a special set of experiences and influences that makes us unique
• Fluid, changes with time, experiences and circumstances
Culture Influences Health Care

- Attitudes and beliefs about health and illness
- Beliefs about causes of disease
- Communication
- Expectations of patients about care providers
- Expectations of care providers about older adults
Impact of Culture on Medical Care

• Need to understand effects of patient’s culture on their interaction with the health care system
• Includes effects of gender, race, ethnicity, sexual identity, socioeconomic status, education and age on an individual person’s identity
• Need for sensitivity and understanding of these influences
Culture Influences Chronic Disease Management of Older Adults

- Traditional “Western” medicine focuses on aggressive management of symptoms and prolonging life
- Other cultures may not have this goal
What is cultural competency?

• Ability of providers and organizations to effectively deliver health services that meet the social, cultural and linguistic needs of patients

• “Includes not only possession of cultural knowledge and respect for different cultural perspectives but also having skills and being able to use them effectively in cross-cultural situations” (Brach and Fraser 2000)

• Cultural humility: commitment to developing mutually beneficial and non-paternalistic clinical relationships with patients and communities
Promoting Cultural Competence

- Seeking out information about the various customs, holidays and religions of cultures different from your own that you will encounter in your work
- Learn how to respectfully ask questions about cultural beliefs
- Respectful curiosity about other people
Cultural Barriers that Affect Communication with Older Adults

- 1. Beliefs
- 2. Expectations
- 3. Stereotyping
- 4. Language
- 5. Health Literacy
- 6. Genetics
- 7. Professional prisms
- 8. Mistrust
- 9. Provider dominance
- 10. Geriatric syndromes
Beliefs

1. Respect: who is respected, including healers, medical professionals, behaviors to show respect such as personal space, body language and words

2. Nutrition/medication: level of acceptance of Western medicine, cultural foods and medications, alternative medications

3. Pain: interpretation of

4. Death: what happens when a person dies, attitudes in interfering with the dying process, advance directives, quality of life issues

5. Time: respect for time, adherence to regimens
Eliciting Explanatory Models of Illness
(Arthur Kleinman, MD, and colleagues)

1. What do you call your problem?
2. What do you think caused it?
3. Why do you think it started when it did?
4. What does it do to you?
5. How severe is it?
6. What do you fear most about it?
7. What are the chief problems it has caused you?
8. What kind of treatment do you think you should receive?
Explanatory Models: Chief Complaint
(76 Cambodian Elders in San Jose)

Contributory: Multiple EMs Cited

Pruiy chiit kiit chraen 68%
Physical Stress 67%
Aging 57%
Imbalance of the elements 53%
Karma 53%
Excess “hot” element 45%
“Wind illness” 41%
Saasey (misalignment) 37%

Source: Handelman & Yeo, 1994
Chronic Care Management of Older Adults

• How do beliefs affect the components of chronic care management?
  • Trust of health care provider and system
  • Collaboration of provider and older adult
  • Adherence, readiness and ability
  • Care plans that are therapeutic and practical
Cultural Barriers

2. Expectations of behavior based on beliefs
   • Need to know each other’s beliefs to have comparable expectations about behavior

3. Stereotyping
   • Exaggerated beliefs or fixed ideas about of individual characteristics and trends
Cultural Barriers: Language

- Need for language assistance services to patients with limited English proficiency
- Family and friends should not be used if at all possible
- Easily understood written material and signage
- Many patients may act like they understand English during brief encounters to please providers
- Use teach-back methods to ensure understanding
Low Health Care Literacy of Older Adults and Families

- Understanding how the body works
- Concept of therapeutic dose
Cultural Barriers

- Mistrust of health care system
- Based on collection of poor health care experiences as individuals and groups
- Lack of patient/provider cultural competence
Genetics

• Understanding the effect of genetics on development of disease
• Treatment response to certain medications
Professional Prism

• Culture of Western medicine
• Lack of understanding of non-Western medicine
Provider Dominance rather than Collaboration

- Provider-focused compliance approach rather than collaborative adherence
- "Conciliatory resistance" as response to dominance
  - Patient says “Yes, yes,” nods in agreement, then goes home and does not follow directions or the agreed-on plan.
  - Despite a well-intentioned deference to the clinician, the patient disagrees with the advice or plan. The problem is that the patient fails to say so in order to avoid confrontation or disagreement
  - In this case, look carefully at the purposeful and unintentional barriers to adherence, such as cost, unpleasant side effects, inability to open the medication container, complicated dosing schedule, and cultural and literacy issues
Cultural Responses to Chronic/Geriatric Syndromes

- Sensory losses: hearing, vision
- Cognitive losses: executive function, depression, dementia
- Syndromes that affect activities of daily living
Solutions for Culturally Competent Care to Older Adults with HIV

1. Recognize barriers to care
2. Ask about beliefs as relevant to goals of the encounter (respect, nutrition, pain, death, time)
3. Work within belief systems
4. Use professional interpreters
5. Verbal and non-verbal communication skills
6. Assess patient’s cultural beliefs
Demonstrating Respect to Older Patients in Culturally Appropriate Ways

- Acknowledge and greet older persons first
- Use formal term of address (Mr., Mrs.) at least initially
- Especially important for populations with historical experiences of discrimination
In some cultures, the “First Name-Last Name” may not fit

Example: traditional Spanish names are 2 last names, mother’s name then father’s name.

Typically prefer to be called by the mother’s name.

For example: Juan Lopez Diaz, “Mr. Lopez” or “Mr. Lopez-Diaz”

In Chinese and Korean cultures, typically the name that is given first is the family name followed by the individual’s name.

For example, Huang Xie would be Mr. Huang

Caveat: some immigrants have changed their names already

If you’re not sure, or don’t have a cultural guide, ask the patient how they would like to be addressed
Non-verbal Communication

- Pace of conversation and tone of voice
- Physical distance
- Eye contact
- Emotional expressiveness
- Gestures
- Touch
Touch

- Etiquette of touch highly variable across and within cultures
- For example, Muslim women may not wish to be examined by male practitioners
- Asking permission for physical exams is a sign of respect for many elders
### LEARN Model for Clinical Encounter

<table>
<thead>
<tr>
<th>L</th>
<th>Listen with empathy and understanding to the patient’s perception of the problem</th>
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<tbody>
<tr>
<td>E</td>
<td>Explain your perceptions of the problem</td>
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<tr>
<td>A</td>
<td>Acknowledge and discuss the differences and similarities</td>
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<td>R</td>
<td>Recommend treatment/solution</td>
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<tr>
<td>N</td>
<td>Negotiate agreement</td>
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<tr>
<td>E</td>
<td>Explanation: older adult explains view of illness and causes</td>
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<td>T</td>
<td>Treatment: older adult explains utilization of personal treatments</td>
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<tr>
<td>H</td>
<td>Healers: older adult explains alternative influences for advice and medication outside of healthcare provider</td>
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<tr>
<td>N</td>
<td>Negotiate: health care plan based on beliefs and readiness</td>
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<td>I</td>
<td>Intervention: finalize an agreed-upon plan of care for specific period of time</td>
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<td>C</td>
<td>Collaboration: work with family, patient and healers to maximize adherence to agreed care plan. Readjust as needed</td>
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Cultural Competency in the Aging Population
What is aging?

• The process of becoming older, accumulation of changes in a human being over time
• “The later part of life, the period of life after youth and middle age...usually with reference to deterioration”
• Number of years defined as “elderly” or “old age” depends on culture/country, from mid-40s to 70s
• Shifting over time due to increased life expectancy
• Very dependent on occupational factors
• Chronological age, psychological factors, social factors
Physical Changes in the Elderly

- Chronic diseases
- Decreased vision, hearing
- Slowed gait, mobility reaction time
Possible Mental Changes in Elderly
(According to Wikipedia)

- Adaptable: more agreeable and accepting
- Caution: antipathy toward risk-taking
- Fear of crime, finances
- Memory loss
- Preference for routine
- Increased religious behavior
Characteristics of the Aging Population

- Eric Erickson’s stages of life
- Ego integrity versus despair
- “Is it OK to have been me?”
- Contemplation of accomplishments, retrospective life review
- Feelings of contentment and integrity if believe they have led a happy, productive life versus despair when looking back at a life of disappointments and unachieved goals
Culturally Competent Care of the Aging Patient

- Stereotypes of the elderly can lead patients and health care workers to dismiss problems as inevitable part of aging
- Older patients are diverse and unique
- Want to be viewed as individuals with wide range of health care needs and questions
Communicating with Aging Patients

• “In the past, older patients held providers in high esteem, treated with deference; likely to change over time as aging baby boomers are likely to take a more egalitarian and active approach to their own health care”

• Patients may not want to “waste the doctor’s time” with minor issues or ask questions in fear of seeming to challenge the clinician

• Important to let older patients know that you welcome questions and participation, to voice their concerns
Communication Skills with Older Patients

- Use proper forms of address (typically formal)
- Ensure comfort of patients (blankets, help completing forms)
- Promote rapport by asking questions about non-medical issues (e.g. family)
- Try not to rush with elderly patients, avoid interrupting
- Demonstrate empathy, “That sounds difficult,” I’m sorry you’re facing this problem, I think we can work on it together.”
- In patients with hearing loss, enunciate clearly and slowly, facing the patient directly, avoid background noise
- Write things down, in font large enough to read
Learning a Life History

• Helps understand the patient
• Strengthens clinician-patient relationship by showing your interest in the patient as a person
• May collect over multiple sessions
• Understanding current functional status
• Attitudes toward relationships with others in family, responses to stress, toward aging, illness, work, death
Cultural Competency in the Aging HIV-Positive Population
In one study, 65% HIV+ patients between 50-59 years of age had at least one co-morbid diagnosis.

7% had medical co-morbidity, substance use disorder and psychiatric diagnosis.

Quality of life linked to addition of chronic health problems.
• HIV-associated inflammation associated with premature onset of aging in multiple organ systems:
  • Renal disease
  • Osteoporosis
  • Cardiovascular disease
  • Lipodystrophy
  • Insulin resistance/diabetes
  • Neurocognitive disorder, dementia
  • Liver disease
  • Cancer
Aging Occurs Faster in HIV+ Patients

- Acceleration of senescence
- Development of co-morbidities 10-15 years sooner than those who do not have HIV
- Thought to be related to chronic inflammation
HIV-Associated Neurocognitive Disorder (HAND)

- Refers to spectrum of cognitive abnormalities related to direct pathogenesis of HIV itself, not from opportunistic infections
- HIV enters into the brain early during the course of infection, causes damage
Changing Epidemiology of HAND

1984-1988
1989-1995
1996-2006

- HIV-associated dementia
- Mild neurocognitive disorder
- Asymptomatic neurocognitive impairment
- Normal

Adapted from 7-9
Symptoms of HIV-Associated Neurocognitive Disorder

- Subcortical structures primarily affected
  - Slowness of accessing thoughts and initiating processes
  - Deficits in working memory
  - Executive function
Symptoms of Mild HIV-Associated Neurocognitive Disorder

- **Cognitive**
  - Impaired attention and concentration
  - Decreased speed of performing tasks
  - Impaired adherence to medications

- **Behavioral**
  - Loss of motivation
  - Social withdrawal
  - Rarely, disinhibition

- **Motor**
  - Change in handwriting
  - Unsteady gait
Symptoms of HIV-Associated Dementia

- **Cognitive**
  - Severe memory loss
  - Severe attention deficits
  - Limited judgment
  - Unable to care for self, progresses to bed-bound

- **Behavioral**
  - Social withdrawal, mutism
  - Rarely, psychosis

- **Motor**
  - Severe slowing, incoordination
  - Spasticity
  - Paraplegia
Screening for Dementia and Neuro-cognitive Disorder in HIV+ Patients

- Mini-Mental Status Examination
- HIV Dementia Scale
- International HIV Dementia Scale
- Montreal Cognitive Assessment
Physical Examination Findings in Patients with HAND

- Often abnormal, especially in advanced disease
  - Hyperreflexia, hypertonia
  - Positive Babinski
  - Paraplegia
  - Rarely choreiform movements

NOT hemiplegia or other isolated focal deficit
Diagnosis of HIV-Associated Neurocognitive Disorder

- Recommend HIV testing in diagnostic evaluation of patients with cognitive impairment/dementia
- Exclusion of other reversible causes of memory impairment (thyroid, RPR etc.)
- In patients with low CD4, evaluation for opportunistic infections
Treatment

• HAART
  • Controversy about which antiretrovirals are best for treatment of this condition
  • Some medications enter into CNS more readily than others ("high cerebrospinal penetration index")
• Adjunctive medications have not been proven effective
HAND

- Milder forms can occur even in stable patients with high CD4 on antiretrovirals
- Unclear etiology; some theories:
  - "Legacy effect"?
    - Previous damage to the central nervous system
  - Additive effects of co-morbidities over time?
    - Aging
    - Substance abuse
    - Atherosclerotic changes
  - Incomplete penetration of ART into CNS?
  - Neurotoxicity of ARVs?
Mental Health in the Aging HIV+ Patient

- Higher rates of depression and suicidal ideation than in general aging population
- Higher rates of substance abuse
- May not have stable, reliable social network for caregiving and advanced decision making
Depression in HIV and Aging

- Increased rates of depression in HIV+ population as compared to general population
- Veterans Aging Cohort study showed depression rates increased with age (although other studies did not show same) (Justice 2004)
- Lower levels of social support associated with increased rates of depression
Screening for Depression

• Consider screening for depressive disorder with standardized measure
• Geriatric Depression Scale minimizes impact of somatic depressive symptoms
• Exclude other causes of depressive symptoms: medication toxicity, hypothyroidism, vitamin deficiencies
Treatment of Depression and Anxiety in Older HIV+ Patients

- No specific recommendations
- Consider “side effects”:
  - Mirtazepine for patients with poor sleep and appetite
  - Venlafaxine for patients with low energy
  - Citalopram with few drug interactions
  - Avoid benzodiazepines if possible in the elderly
Aging in Older HIV-Infected Adults

- Many HIV+ older adults report “double stigma” of ageism and HIV-associated stigma
- May have symptoms of isolation from traditional social supports
- In studies, patients often report uncertainty, worrying about the future
- “A shrinking kind of life”
Aging with HIV and Co-Morbidities

• Study interviewed HIV+ African American women age 52-65
• Co-morbidities, including diabetes and hypertension, perceived by patients to be more difficult to self-manage than HIV
• Related to lack of health insurance, inflexible work schedules, loneliness
• Social responsibilities, taking care of family, positively impacted patients in this study

• AIDS Patient Care & STDs 2014.
Aging with HIV

- Women may feel isolated and inhibited from seeking social connection due to reluctance to disclose HIV status
- Report feeling “shame” at their older age
- Spirituality as a great support for many women, although fear of disclosure may limit connections with a church community
Management of Aging in HIV+ Patients
Case Study

- 65 y/o African American female presents to outside clinic with decreased taste sensation
- PMH: hypertension, diabetes, poor dentition → edentulous
- Social history: no alcohol, drugs, smoking; lives alone (husband died of lymphoma several years previously)
- Physical exam: mild whitish exudates on dorsal tongue
- Diagnosis: thrush, thought to be related to dentures
- Treated with fluconazole, symptoms resolve
Case Study

- Patient presents with recurrent disease 2 more times
- Eventually has upper endoscopy which shows candidal esophagitis
- Treated with high-dose fluconazole and symptoms resolve
Case Study

• Presents to hospital with severe pneumonia requiring intubation
• Initially not responsive to broad-spectrum antibiotics
• Bronchoscopy performed, showing:
  • *Pneumocystis jiroveci*

• Treated with trimethoprim-sulfamethoxazole and recovered
• HIV-1 antibody positive. CD4 was 6 cells/μL
Case Study

- Presents to Parkland clinic
- Started on Atripla (efavirenz/emtricitabine/tenofovir)
- Very adherent to medications and appointments
- Viral load becomes undetectable, CD4 in 300s-400s
Case Study: 2015

- Still followed at Parkland clinic, currently age 81
- Current health issues:
  - Symptoms today: “arthritis”; insomnia
  - Hypertension, well-controlled
  - Hyperlipidemia
  - Creatinine 1.0 mg/dL
  - Low weight
  - Daughter concerned about possible memory problems
  - Health maintenance, including bone health
New Diagnosis of HIV in Older Adults
Detection and Screening for HIV in Older Adults

- Important to detect HIV in the aging patient
- 1/6 cases of new HIV infections in the US diagnosed in those >50 years of age
- Often symptoms of advanced AIDS can mimic symptoms of “failure to thrive” from other causes seen in the elderly
Late Diagnosis of HIV in Aging Population

- Older adults more likely to present later in infection with more advanced disease and increased mortality
- Study from United Kingdom showed that 48% of older adults diagnosed within 1 year of AIDS diagnosis as compared to 33% of younger adults (Smith 2010)
- 14 times more likely to die within 1 year of diagnosis compared to older adults diagnosed earlier
Screening for HIV/AIDS in Older Populations

• Awareness of potential risk factors by providers and patients is lacking

• Main risk factor for HIV acquisition in older patients is heterosexual intercourse (Grabar 2006, Martin 2008, Sherr 2009)

• Older women may be at increased risk for HIV due to age-related vaginal thinning and dryness, issues of disclosure and decreased use of condoms
Screening for HIV

- CDC guidelines for “universal” opt-out testing for all patients between ages of 13-65
- Some experts recommend universal testing regardless of age
  - HIV testing is relatively inexpensive and cost-effective
  - One of the few treatable causes of dementia and other causes of “failure to thrive”
Management of HIV+ Older Adults
Multiple cohort studies of untreated HIV+ patients show that older patients have more rapid progression to AIDS and shorter survival than younger patients (Phillips 2008, Egger 2002).

Retrospective analysis of study found that ARVs improved survival rates in patients >50 years of age (Perez 2003).
Initiation of ARV in Older Adults: When to Start

- Overall recommendation in United States and worldwide to start antiretroviral therapy earlier in the course of infection
- Randomized controlled trial “START” evaluation of initiation of ARVs at CD4 >500 cells/μL in asymptomatic patients
- Included older patients within the study
What to Start in the Older HIV+ Patient

- Few randomized, controlled ARV trials include older patients
- Some organizations (American Academy of HIV Medicine) recommend avoidance of ritonavir-boosted protease inhibitor-based regimen if possible due to lipid side effects
- Some clinicians would avoid tenofovir-containing regimens due to effects on bone and renal health
- Abacavir and possible cardiovascular risk
- Tenofovir alafenamide to avoid some of these toxicities
Drug-Drug Interactions and Polypharmacy

• Increased prevalence of co-morbidities with increased age
• Additional medicines added by providers to treat co-morbidities, including subspecialty providers
• Drug-drug interactions very common, particularly with antiretrovirals
Drug-Drug Interactions and Polypharmacy

- Primary care provider should perform medication reconciliation and review at every visit
- Recommended to use one pharmacy, including integrated pharmacy network
Multi-Morbidity

- Several serious health conditions which cannot be cured
- Causing functional and/or cognitive debility
- Many aging patients with HIV have multiple co-morbidities
- Following all the professional guidelines for treatment and prevention of specific, resulting treatment regimen is very complex and with complicated dosing pattern (Boyd 2005)

- “When considering treatment options in persons with multi-morbidity, the sum is greater than the parts”
Considerations in the Aging Patient with HIV

• Renal disease
  • Screening for renal disease
  • Avoid nephrotoxins
  • Treating blood pressure
• Osteoporosis: DEXA screening
• Cardiovascular disease: daily aspirin, management of lipids, blood pressure
• Lipodystrophy
• Insulin resistance/diabetes
• Neurocognitive disorder, dementia: ?screening
• Cancer: screening?
Advanced Directives

- Common early in HIV epidemic for all patients engaged in care to have durable power of attorney, advanced directives, living wills
- As prognosis from HIV improved, the practice of holding end-of-life discussions decreased
  - Only 50% had discussed end-of-life issues with PCP
  - 38% completed advanced directive (more likely if provider discusses)
Advanced Directives

• Important to discuss with patients when they are healthy to be aware of their wishes
  • Patients may not wish to have legally defined “next of kin” to make medical decisions for them
  • “Physician Orders for Life Sustaining Treatment” 2010
  • “Five Wishes”
Aging Patients with HIV

- Individualized treatment strategy for patients in respect for their cultural beliefs
- Shared decision making on aggressiveness in management of chronic conditions and preventative screening
- Based on individual patient’s values and preferences (AAHIVM):
  - What are most important outcomes for a patient?
  - What burdens are they willing to endure in order to achieve these outcomes?
  - What are their preferences regarding potential harms associated with interventions?
  - How does the level of uncertainty surrounding the reported benefits of treatment affect your decision making process?
Summary

- Our patients with HIV are growing older
- Increasing numbers of co-morbidities
- Complex to manage co-morbidities in fragile patients, increasing pill burdens and side effects
- Importance of patient autonomy and partnership with patient with shared decision-making
Questions?