Engaging HIV+ Older Adults in Chronic Disease Self-Management Education

July 19, 2016

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- Dr. Kate Lorig, Stanford Patient Education Research Center
- Christy Hudson, Oregon Health Authority
- Marty Fobes, Oregon Health Authority
The Status of the Aging HIV Epidemic: Multimorbidity Management

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AIDS Community Research Initiative of America
ACRIA Center on HIV and Aging
New York University College of Nursing
New York, NY
How Did We Get Here?

Effective HIV Treatment

New HIV Infections in Older Adults
It takes 10 years for the virus to cause the collapse of the immune system resulting in AIDS.

ART treatment stops that collapse.

HIV Infection

ART

AIDS
Median Life Years at Age 20 With HIV In-Care and Early Detection

### % of all PLWH in the US by Age Group for 2010

**CDC Surveillance Data**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Est 2015</th>
<th>(Est 2015 + Est 2020)</th>
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</thead>
<tbody>
<tr>
<td>&lt;13</td>
<td>0.3%</td>
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<tr>
<td>13–14</td>
<td>0.1%</td>
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<td>15–19</td>
<td>0.8%</td>
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<td>20–24</td>
<td>3.4%</td>
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<td>25–29</td>
<td>5.8%</td>
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<td>30–34</td>
<td>8.1%</td>
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<td>35–39</td>
<td>10.5%</td>
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<td>40–44</td>
<td>16.0%</td>
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<tr>
<td>45–49</td>
<td>19.7%</td>
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<tr>
<td>50+</td>
<td>35.2%</td>
<td>(35.20% + 19.70%)</td>
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</table>

**Estimates:**
- Est 2015: 54.9% (35.20% + 19.70%)
- Est 2020: 70.9% (54.9% + 16.01%)
NYC is the North American Epicenter of the Epidemic
There are 110,000 People with HIV in the City

% of PLWHA AGE 50 and Older in NYC

- Year
Estimates of the USA HIV Epidemic Causes for Increasing numbers of Non-AIDS

The Aging of the HIV Epidemic in the United States

CDC Surveillance Data

- Number of people living with HIV
  - Over age 50 in 2011: 37%
  - Over age 50 in 2015: 50%
  - Over age 50 in 2020: 70%

1.25 Million
Today HIV treating providers are spending more time managing non-AIDS diseases.
THE COMPLICATION OF SUCCESS
Many Age-Associated Diseases are More Common in Treated HIV Patients than in Age-Matched Uninfected Persons

- Cardiovascular disease
- Cancers
- Bone fractures; osteopenia
- Liver Failure
- Kidney Failure
- Frailty
- Cognitive Dysfunction
- Frailty
- Hearing Loss & Macular Degeneration
From initial HIV infection there is a cascade of inflammation that occurs.

It is not stopped but only blunted by HIV treatment.
HIV production
HIV replication

Loss of regulatory cells

Inflammation
↑ Monocyte activation
↑ T cell activation
Dyslipidemia
Hypercoagulation

HIV-associated fat Metabolic syndrome

CMV
Excess pathogens

Microbial translocation

Co-morbidities
Aging
Inflammation predicts disease risk in those on ART and in the general population

- **Cardiovascular Disease** (Baker, CROI 2013)
- **Lymphoma** (Breen, Cancer Epi Bio Prev, 2010)
- **Venous Thromboembolism** (Musselwhite, AIDS, 2011)
- **Type II Diabetes** (Brown, Diabetes Care, 2010)
- **Cognitive Dysfunction** (Burdo AIDS 2012)
- **Frailty** (Erlandson, JID 2013)
Comorbidity Prevalence Among People With HIV Is Increasing

Trends in Comorbid Conditions: Medicare HIV Patients

*Significant at p<.05 for 2003 vs. 2013

- CV Event**: 9.6% (2003), 9.2% (2013)
- Renal impairment: 20.1% (2003), 11.2% (2013)
- Fracture/osteoporosis: 6.7% (2003), 34.2% (2013)
- Hypertension: 65.1% (2003), 31.1% (2013)
- Diabetes: 20.4% (2003), 0% (2013)
- Obesity: 0.0% (2003), 6.3% (2013)
- Hyperlipidemia: 12.1% (2003), 47.5% (2013)

Meyer, ICAAC, 2015
% Number of Comorbid Illnesses 0-6+ for Each Person: ROAH HIV+ vs USA (NHANES) Age 50+ (2006)

Submitted ACRIA 2016 Ambroziak, A…Karpiak, S.E.
During five-year period, % of patients prescribed at least one ARV/non-ARV combination that was contraindicated or had moderate or high evidence of interaction (N=1,534)

Are Older Adults with HIV Aging Differently?

Are they experiencing accelerated aging?

Considering all of the risk factors that are not HIV specific – that hypothesis remains to be proven
HIV-Infected Older Adults Challenged by Multimorbidity but Not Accelerated Aging

Commentary  December 19, 2015

Increasingly providers of clinical care for people living with HIV are spending less time managing drug resistance and associated short term ART toxicities and more time managing age associated illnesses. This shift in care is underlined by reports that most deaths for this population are a result of non-AIDS related illnesses. This caused many to ask – are people infected with HIV aging faster? The words “accelerated aging” are often used to describe the aging trajectory of the older adult with HIV. This perception was reinforced by multiple research reports which show older adults are developing illnesses typically associated with aging and in some cases at an earlier age than would be expected.

In 2010 Martin and Volberding remind us that accelerated aging in the HIV older adult is an “intriguing” hypothesis, and, that we should not allow it to become ingrained in the culture of HIV before it has been supported. Yet, by 2015 the common perception exists that accelerated aging is manifested in older adults with HIV.

Testing the hypothesis “Does HIV cause accelerated aging?” requires finding comparison groups that are adequate to yield valid results. Researchers must control as many variables as possible in order to isolate the HIV effect. But, as a group, HIV-
IS THIS REALLY ALL ABOUT
RISK
and
NOT HIV
Non-HIV RISK Factors that Characterize HIV Older Adults

- Smoking (50-65%)
- History of Substance Use
- Poor Diet/Food Scarcity
- No Exercise
- 1/3 Co-infected with HepC
- Minimal Alcohol Use is Detrimental
- Stress from Chronic Depression
- Low Socio Economic Status/Resource
- Stigma Induced Social Isolation
- Not working
- Long Term Opioid Use
• HIV-positive men who smoke can expect to lose almost 8 years off their life expectancy.

• Smokers with HIV were 1.94 times more likely to die than nonsmokers.

• Smokers with HIV were 6.28 times more likely to die of cardiovascular disease.

• Smokers with HIV were 2.67 times more likely to die of non-AIDS cancers when compared with nonsmokers.

Cost per year for ART

• $25,500

Cost to Cure HepC

• $100,000

Cost for one year of food in USA

• $6,000
Aging Leads to Diminished Reserve

Frailty and Function

Ethnographic data….
Frailty-like syndrome occurs earlier in HIV disease (predicted by CD4 nadir)

Frail state is associated with elevated levels of immune activation
Geriatric Syndromes in the SCOPE Cohort > 50 y

Greene, JAIDS, 2015

Median Age: 57 (IQR: 54, 62)
Psychosocial variables that are forgotten or given at best tertiary consideration
Research on Older Adults with HIV

Demographics
Sexual Behavior
Social Networks
Psychological Well-Being
Distress – Depression
HIV Status/Health
Religiousness & Spirituality
Loneliness Among Older Adults
HIV Stigma and Disclosure
Rates of Depression are 3-5 Times Higher in Older Adults with HIV

ROAH: CES-D Symptoms of Depression

- Severe (23+): 43%
- Not Depressed (1 to 15): 37%
- Moderate (16-22): 20%
Over 2/3 of the study group had moderate to severe depression.

Depression Causes Non-Adherence to ALL Medication including HIV Meds.

Although in Medical Care Their Depression Remains Unmanaged.
Proportion Living Alone: ROAH vs. Community-Dwelling NYC Elderly

- **ROAH**: 70%
- **HIV/AIDS**: 39%

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ROAH: % Primary Relationship Status

Brennen et al., 2009
### ROAH: Co-occurrence of Substance Use and Behavioral Health Issues

<table>
<thead>
<tr>
<th>Recovery Status</th>
<th>%</th>
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<tbody>
<tr>
<td>Ever enrolled in 12-step</td>
<td>62</td>
</tr>
<tr>
<td>Currently in recovery</td>
<td>54</td>
</tr>
<tr>
<td>No substance use in past 3 months</td>
<td>48</td>
</tr>
<tr>
<td>In recovery for more than 1 year</td>
<td>44</td>
</tr>
</tbody>
</table>
Need for Multimorbidity Management
Aging is Not A Disease

External Changes
- Thinning and greying of hair
- Wrinkles and loose skin
- Loss of Muscle mass
- Vision Changes

Internal Changes
- Reduction in Number and Effectiveness of Immune cells (Immunosenescence)
- Increase in destructive Proteins (Inflammation)
## Patient Factors

<table>
<thead>
<tr>
<th>Non-Modifiable</th>
<th>Modifiable</th>
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<tbody>
<tr>
<td>Age</td>
<td>Weight</td>
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<tr>
<td>Sex</td>
<td>Smoking</td>
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<tr>
<td>Genes</td>
<td>Alcohol</td>
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<td></td>
<td>Illicit Drugs</td>
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<td></td>
<td>Exercise</td>
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<td>Diet</td>
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<td></td>
<td>Adherence to ART</td>
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</tbody>
</table>
This multi-morbidity contributes to overlapping injury to multiple organ systems

(Justice 2010; Deeks & Phillips 2009).

The result is the transformation of HIV infection into a complex chronic disease associated with multi-morbidity requiring the attention and expertise of multiple health care domains and their providers (Sevick et al. 2007).
Siloed Care  Integrated Care

Grand Opening: The Go-To Place On HIV And Aging
Editorial February 5, 2014 3 Comments

In the U.S. the HIV population is aging. By 2015 half of the over 1.4 million people infected with HIV will be age 50 and older. Each day 80 more people become part of this older adult group. And, 1 in every 6 new HIV diagnoses occurs in the age 50 and older population. This graying of... Continue Reading

Card For Clinicians Caring For HIV-Infected Older Adults
Science Spotlight February 5, 2014

CARD FOR CLINICIANS CARING FOR HIV-INFECTED OLDER ADULTS The Quick Reference Card for Managing Older Adults with HIV was developed out of the New York State Dept. of Health AIDS Institute Office Of The Medical Director. To obtain a copy, access www.hivguidelines.org. The AIDS Institute determined HIV and Aging as a priority over ten years ago. The number... Continue Reading
Geriatric Care Principles

- Patient-Centered Care
- Social Supports
- Patient Involvement in Care Decisions
- Polypharmacy
- Integrated Care
HIV

Cancer – Cardiovascular Disease
Osteoporosis – Liver and Kidney Disease - Diabetes

Mental Health

Social Factors

Multimorbidity Care Management
Conclusions

- With the aging HIV population, multi-morbidity is increasingly common
- Multi-morbidity will have profound effects on lifespan and health-span in older HIV-infected persons
- Interventions and infrastructure will be needed to prevent and treat multi-morbid conditions and their consequences.
1 in every 6

New HIV Diagnoses Occurs in Older Adults Age 50 and Older
AGE
Is not
A CONDOM
Thank you.....

Stephen E Karpiak PhD
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Positive Self-Management Program (PSMP)

Kate Lorig

http://patienteducation.stanford.edu

650-723-7935

http://patienteducation.stanford.edu
What Is PSMP?

► Face-to-face small group program for people who are HIV positive
► Facilitated by 2 peer Leaders
► Offered in community settings
► Six weeks
► Recently revised 2015
What is taught?
<table>
<thead>
<tr>
<th>Workshop Overview</th>
<th>Week1</th>
<th>Week2</th>
<th>Week3</th>
<th>Week4</th>
<th>Week5</th>
<th>Week6</th>
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<tr>
<td>Overview of self-management and long term health</td>
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<tr>
<td>conditions</td>
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<tr>
<td>Using your mind to manage symptoms</td>
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<td>Monitoring HIV</td>
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<tr>
<td>Making an action plan</td>
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<tr>
<td>Feedback on action plan</td>
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<td>Problem-solving</td>
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<td>Managing fatigue</td>
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<td>Making decisions</td>
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<td>Dealing with difficult emotions</td>
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<td>Working with your healthcare team</td>
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<tr>
<td>HIV Medications</td>
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<tr>
<td>Better breathing</td>
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<tr>
<td>Relaxation body scan</td>
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<tr>
<td>Dealing with depression</td>
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<tr>
<td>Physical activity &amp; exercise</td>
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<td>Sex, intimacy &amp; telling others</td>
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<td>Communication skills</td>
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<tr>
<td>Healthy eating</td>
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<tr>
<td>Getting a good night’s sleep</td>
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<tr>
<td>Future planning &amp; legal issues</td>
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<tr>
<td>Positive thinking</td>
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<td>●</td>
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<tr>
<td>Weight management</td>
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<tr>
<td>Building support systems</td>
<td></td>
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<tr>
<td>Accomplishments</td>
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</table>
Where is it offered?

- 23 states
- Seven countries

http://patienteducation.stanford.edu/organ/psmpsites.html
Evidence 1998

- Decrease in symptoms severity
- Increase in self-efficacy
- Trend toward greater exercise in treatment group

Evidence 2006

- No differences between groups in medication adherence or symptoms
- Improvement in disclosure worries and in mastery of HIV skills

HIV is now a chronic disease BUT…

- Disclosure continues to be an issue
- Medication adherence is a public health issue as well as an individual issue
- Sexual orientation and gender identity are issues for some
What if we want to offer PSMP?

► Many Master Trainers in the United States

► If someone is already trained in CDSMP, they can receive cross-training from Stanford via web videos and webinar
HIV Positive Self Management Program

Christy Hudson, MSW
HIV Services Coordinator
HIV Care & Treatment Program, OHA

Marty Fobes, RN, ACRN
PSMP Facilitator
Technical Assistance

The TARGET center provides a variety of resources like documents, Webcasts and more.

Learn More
Figure 1. Ryan White Funding, FY2016
Total = $2.3 billion
Ryan White Part B Programs in Oregon

- CAREAssist (Oregon’s AIDS Drug Assistance Program)
- Case Management & Support Services (through contracts with local health departments and community based organizations)
- Permanent Supportive Housing (HUD funded)
## PSMP – Estimated Budget/Workshop

<table>
<thead>
<tr>
<th>Items</th>
<th>Estimated Cost</th>
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</thead>
<tbody>
<tr>
<td>Trainer/Peer Leader</td>
<td>$3,000</td>
</tr>
<tr>
<td>Travel &amp; Lodging</td>
<td>$3,560</td>
</tr>
<tr>
<td>Materials/Client Incentives</td>
<td>$500</td>
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<tr>
<td>Allocation for PSMP License</td>
<td>$20</td>
</tr>
<tr>
<td>Total for training</td>
<td>$7,080</td>
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</table>
## Information & Referral

### Positive Self-Management Program (PSMP) screening

Did client report any of the following problems? *(Check all that apply)*

- [ ] Difficulty integrating medications into daily life so can be taken consistently
- [ ] Struggles with frustration, fear, fatigue, pain, depression and isolation
- [ ] Challenges maintaining appropriate exercise for improving strength, flexibility and endurance
- [ ] Problems communicating effectively with family, friends and health professionals
- [ ] Disclosure issues
- [ ] Nutrition concerns
- [ ] Difficulties evaluating symptoms
- [ ] Questions regarding advanced directives
- [ ] Ability to understand new or alternative treatments

Have you ever taken the Positive Self-Management Class?  [ ] Yes  [ ] No

Would you be interested in more information regarding a free class for persons living with HIV/AIDS called *Positive Self-Management Program*?  [ ] Yes  [ ] No

### Comments:

**Plan:** Refer to PSMP (Marty Fobes, ACRN - 541-602-8444)?  [ ] Yes  [ ] No

Would you like to be notified about health education classes?  [ ] No  [ ] Yes
Outreach

- Flyer mailed, and emailed
- Enclosed with cover letter from case manager
- Incentives provided
- Caregivers/partners invited
- Register via text, phone or email
Program Outcomes

- 4 – 5 sessions offered per year, with 8 – 10 participants each session
- 80% of participants attend at least 5 sessions
- Clients incorporating self management tools
- Clients connecting with family members
- Increased support within the group
- Clients reported increased knowledge

“ I’ve met new friends and feel supported.”

“I appreciate being in the presence of other HIV+ folks.”

“I hadn’t felt comfortable in a group situation in the past and appreciated the support of the group”

“I didn’t think I would last a week but learned so much, I would take it again”
Barriers to Implementation

• Location to hold the sessions

• Smaller communities where transportation is an issue

• Large geographic areas – clients are spread out

• Making the commitment to attend weekly meetings

• No show after clients register
Recommendations for Implementation

• Partner with existing Ryan White provider, or AIDS Service Organization

• Plan well in advance

• Remove transportation barriers

• Stigma considerations
Thank you!

Christy Hudson
Christy.j.hudson@state.or.us

Marty Fobes
mafconsulting1@gmail.com
Questions & Answers

Type your question into the chat box on the lower left-hand side of your screen.

For reference, the recording of this webinar will be e-mailed to all webinar attendees and posted shortly on www.ncoa.org/cha.