An In-depth Examination of an Emerging Population

Who Are These Older Adults Living with HIV

Stephen Karpiak PhD
ACRIA Center on HIV and Aging
Skarpiak@acria.org
New York University College of Nursing
ACRIA: AIDS Community Research Initiative of America
founded in NYC in 1991

Clinical Trials
- Antiretrovirals
- Side-effects management
- Comorbid treatments

Research on Older Adults
- Social networks
- Depression management
- Comorbidities
- Service utilization
- Accessing caregivers
- Stigma
- Spirituality

Education Health Literacy
- Staff/agency trainings on needs of aging HIV populations & those at-risk
- Local and national technical assistance & capacity building
- Continuing education credits
- Materials in several languages
Older Adults with HIV:
An In-depth Examination of an Emerging Population
Editors: M. Brennan, S. E. Karpiak, M. H. Cantor & R. A. Shippy

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Substance and Alcohol Use; A. Applebaum & M. Brennan

Sexual Behavior among HIV+ Older Adults; S. A. Golub, C. Grov, & J. Tomassili

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About the Authors

Appendix: Methodology of the ROAH Study
Impact of HAART

Mortality (x 1000)

PLWHA (x 10,000)

Source: NYC Dept of Health & Mental Hygiene, 2004
USA AIDS Cases Over Age 50 - CDC

- 1995: 20,000 cases
- 2005: 130,000 cases
Estimated Number of Persons Living with HIV/AIDS - Diagnosis by Age, 2001-2004 *

*CDC HIV/AIDS Surveillance Report, 2004
New York City is the US HIV Epicenter

Today in NYC there are approximately 120,750 known people living with the HIV
38 %

of people with HIV/AIDS in NYC are Over 50

74 %

of people with HIV/AIDS in NYC are Over 40
The Aging of the HIV NYC Population (OVER 50)

- New Diagnoses
- People Living with HIV
By 2013, One-half of Persons Living with HIV in NYC will be 50 Years and Older

Projected Percent of People Living With HIV/AIDS in NYC 50+

By Mark Brennan, PhD
ACRIA Center on HIV and AGING
<table>
<thead>
<tr>
<th>State</th>
<th>Over 50</th>
<th>Over 40</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Francisco</td>
<td>35 %</td>
<td>76 %</td>
</tr>
<tr>
<td>Los Angeles</td>
<td>33 %</td>
<td>77 %</td>
</tr>
<tr>
<td>Missouri</td>
<td>35 %</td>
<td>76 %</td>
</tr>
<tr>
<td>Illinois</td>
<td>32 %</td>
<td>74 %</td>
</tr>
<tr>
<td>Wisconsin*</td>
<td>38 %</td>
<td></td>
</tr>
<tr>
<td>Michigan*</td>
<td>38 %</td>
<td></td>
</tr>
</tbody>
</table>

* HIV/AIDS
Concurrent HIV/AIDS among persons diagnosed with HIV in 2006 by age group, United States

ACRIA: First Studies Conducted in 2004

ACRIA conducted an initial study of 150 older adults – over the age of 50 – living with HIV in NYC.

That study resulted in multiple presentations, abstracts and two peer review published articles:


Research on Older Adults with HIV

Investigators
Stephen E. Karpiak, PhD
Mark Brennan, PhD
ACRIA Center on HIV and Aging
ROAH Research Collaborators/Advisory Group

Chairperson: Marjorie Cantor, Emerita Fordham U & Brookdale Scholar

Stephen Bailous
J. Bookhard-Murray, MD
David Dorfman, PhD
Arlene Kochman, MSW
Allen Matthews, Mardi Fritz
Douglas Mendez, MD
Peter Nwakeze, PhD
Jeffery Parsons, PhD
Cynthia Poindexter, PhD
Bobbie Sackman, MSW
J. Edward Shaw
J. Lee Westmaas, PhD
Desieree Byrd, PhD
Richard Havlik, MD

Office of AIDS Policy, NYC DOH
Medical Director Harlem United & AIDS Institute NYS
Mt. Sinai School of Medicine
Yale University School of Medicine
NYC DOH
Dominican Medical Association
NYC Association for HIV Over 50 and Hunter College
CHEST & Hunter College
Fordham University Graduate School of Social Service
NYC Council of Senior Centers, Director of Public Policy
NYC Commission on AIDS
SUNY, Dept of Psychology
NeuroAIDS, Mt Sinai
NIA/NIH Section Chief
ROAH’s Data Dissemination Includes

1. Publications in Peer Reviewed Journals
2. Book Chapters
3. Symposia at the
   - Gerontological Society of America
   - American Psychological Association
   - American Public Health Association
   - New York State Society on Aging
4. Invited Presentations at Medical Schools and Academia including
   - Columbia University
   - Washington University
   - New York University
   - Johns Hopkins
   - Mt. Sinai
   - Oxford University
   - University of Maine
5. Collaborative Efforts: NYU School of Nursing, Chelsea-Westminster Hospital in London, Fordham University, Hunter College (CHEST)
ROAH Modules

- Demographics
- Sexual Behavior
- Social Networks
- Psychological Well-Being
- Distress – Depression
- HIV Status/Health
- Religiousness & Spirituality
- Loneliness Among Older Adults
- HIV Stigma and Disclosure
ROAH Study Design

Purpose: A Profile
To establish empirically valid normative data describing the growing and changing population of older adults with HIV

Participants (total $N = 1000$)
NYC community-dwelling, HIV-positive adults over 50

Procedure
Participants completed a self-administered survey after giving informed consent. Assessment tools include standardized tests.

HIPAA Compliant and IRB Approved
Demographics
Long-term survivors living with HIV/AIDS for 10 to 25 years

- Male 69%
- Female 31%

Race:
- Black 44%
- Latino 32%
- White 21%

Sexual Orientation:
- Heterosexual 67%
- Bisexual 9%
- Homosexual 24%
## ROAH Demographics

### Employment Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working</td>
<td>8.3</td>
</tr>
<tr>
<td>Retired</td>
<td>6.9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20.1</td>
</tr>
<tr>
<td>Disability</td>
<td>64.2</td>
</tr>
</tbody>
</table>

### Country of Birth

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>83.5</td>
</tr>
<tr>
<td>Other nation</td>
<td>16.5</td>
</tr>
</tbody>
</table>

### Education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
<td>20.4</td>
</tr>
<tr>
<td>High school graduate</td>
<td>58.6</td>
</tr>
<tr>
<td>College graduate</td>
<td>21.5</td>
</tr>
</tbody>
</table>
% with AIDS Diagnosis

- White
- Black
- Latino
## ROAH HIV Care

### Currently Taking ARVs

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>87.3</td>
</tr>
<tr>
<td>Latino</td>
<td>84.8</td>
</tr>
<tr>
<td>White</td>
<td>85.3</td>
</tr>
<tr>
<td>Male</td>
<td>86.0</td>
</tr>
<tr>
<td>Female</td>
<td>83.0</td>
</tr>
</tbody>
</table>
### ROAHH IV Care

83% Medicaid Dependent

<table>
<thead>
<tr>
<th>Treatment facility</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private physician</td>
<td>21.9</td>
</tr>
<tr>
<td>Public clinic / hospital</td>
<td>58.7</td>
</tr>
<tr>
<td>VA Hospital</td>
<td>4.9</td>
</tr>
<tr>
<td>ASO / day program</td>
<td>17.0</td>
</tr>
</tbody>
</table>
## ROAH HIV Measures

<table>
<thead>
<tr>
<th>Years since diagnosis</th>
<th>X</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>13.1</td>
</tr>
<tr>
<td>Female</td>
<td>11.4</td>
</tr>
<tr>
<td>White</td>
<td>14.9</td>
</tr>
<tr>
<td>Black</td>
<td>11.8</td>
</tr>
<tr>
<td>Latino</td>
<td>12.9</td>
</tr>
</tbody>
</table>
More than 80% rely on Medicaid

54% are currently in recovery

Half of their friends do not know they are HIV+

Almost 70% live alone

Only 15% have a spouse or life partner
Proportion Living Alone:
ROAH vs. Community-Dwelling NYC Elderly
Years Since HIV Diagnosis by LGBT Status
Transmission Mode in ROAH: The Changing HIV Population

- Unprotected Vaginal: 60% (6-10 years)
- Sharing Needles: 40% (6-10 years)
- Unprotected Anal: 20% (6-10 years)

_age groups: > 10 years, 6-10 years, 1-5 years
Stigma
ROAH: Disclosure of HIV Status

- Healthcare: 90%
- Sexual partners: 70%
- Family: 60%
- Friends: 50%
- Social groups: 40%
- Drug buddies: 30%
- Co-Workers: 20%
- Place of Worship: 30%
Figure 3 Proportion of Respondents Wanting to Disclose HIV Status to Others by Race/Ethnicity
Comorbidities

Richard Havlik, MD
Ret. Section Chief NIA
ACRIA Consultant and Collaborator
ROAH Self Report Data

Comorbid Health Problems

- Depression
- Arthritis
- Hepatitis
- Neuropathy
- Hypertension
- Dermatologic...
- Herpes
- Vision loss
- Diabetes
- Neurological...
- STD
- Hearing loss
- Pneumonia
- Respiratory...
- Heart condition
- Broken bones
- Shingles
- Migraines
- Cancer
- Stroke
- Staph. infection

Percent
Figure 1: Prevalence of HIV-related, Age-related, Chronic, and Other Comorbidities in Older Adults with HIV.
Average Number of Comorbidities

- Elderly 70+
  - Average number of comorbidities: 1

- ROAH
  - Average number of comorbidities: 4
## ROAH: Summary  Depressive Symptoms and Comorbidities

<table>
<thead>
<tr>
<th>Condition</th>
<th>Significance</th>
<th>% No Depressive Symptoms</th>
<th>% Moderate Depressive Symptoms</th>
<th>% Severe Depressive Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision Loss</td>
<td>p&lt;0.01</td>
<td>18.3</td>
<td>27.5</td>
<td>54.2</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>ns</td>
<td>28.2</td>
<td>21.4</td>
<td>50.5</td>
</tr>
<tr>
<td>Dermatological Problems</td>
<td>p&lt;0.05</td>
<td>24.7</td>
<td>23.5</td>
<td>51.8</td>
</tr>
<tr>
<td>Heart Condition</td>
<td>p&lt;0.05</td>
<td>26.6</td>
<td>20.2</td>
<td>53.2</td>
</tr>
<tr>
<td>Respiratory Condition</td>
<td>p&lt;0.01</td>
<td>20.2</td>
<td>20.2</td>
<td>59.6</td>
</tr>
<tr>
<td>Stroke</td>
<td>p&lt;0.05</td>
<td>13.8</td>
<td>41.4</td>
<td>44.8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>ns</td>
<td>32.6</td>
<td>19.4</td>
<td>48.1</td>
</tr>
<tr>
<td>Broken Bones</td>
<td>p&lt;0.01</td>
<td>19.2</td>
<td>33.3</td>
<td>47.4</td>
</tr>
<tr>
<td>Impotence</td>
<td>ns</td>
<td>29.4</td>
<td>21.0</td>
<td>49.6</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>ns</td>
<td>33.5</td>
<td>23.6</td>
<td>42.9</td>
</tr>
</tbody>
</table>
Implication

We need to develop a more integrated approach to manage the health of those older adults living with HIV.
Substance Use
<table>
<thead>
<tr>
<th>Current %</th>
<th>History %</th>
</tr>
</thead>
<tbody>
<tr>
<td>57</td>
<td>84</td>
</tr>
</tbody>
</table>
## ROAH: Substance Use Recovery

<table>
<thead>
<tr>
<th>Recovery Status of Substance Users</th>
<th>%</th>
</tr>
</thead>
<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>
Social Networks
CAREGIVERS are derived from SOCIAL NETWORKS.
ROAH: Informal Network Composition

- Parent
- Child
- Sibling
- Other Relative
- Friend

□ Living
ROAH: Informal Network Composition

- Parent
- Child
- Sibling
- Other Relative
- Friend

□ Living □ Functional
ROAH: Sexual Behavior

Center for HIV/AIDS Educational Studies (CHEST) @ Hunter College
City University of New York
Drs. Golub, Grov, Tomaselli, Parsons
### ROAH Sexual Behaviors 3MOS

<table>
<thead>
<tr>
<th>Number of sexual partners</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No sexual partners</td>
<td>43.3</td>
</tr>
<tr>
<td>One sexual partner</td>
<td>43.4</td>
</tr>
<tr>
<td>More than one sexual partner</td>
<td>13.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexual activity in the last 3 months</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No sexual activity</td>
<td>49.8</td>
</tr>
<tr>
<td>Oral sex</td>
<td>41.4</td>
</tr>
<tr>
<td>Vaginal sex</td>
<td>30.1</td>
</tr>
<tr>
<td>Anal sex</td>
<td>19.5</td>
</tr>
</tbody>
</table>
Figure 3  Unprotected Sex and Serosorting among Older Adults with HIV
- Substance use impact - Significant
- Viagra and other ED Drugs Impact - None
- Of those who are sexually active
  16% engaged in high risk sexual behavior in the last 3 months
Depression
Depression Among PLWH

- Several studies report that depression can suppress immune responses (e.g., Tiemeier, van Tuijl, Hofman, Kiliaan, & Breteler, 2003)
- Kiecolt-Glaser and Glaser (2002) found depression to be associated with an increased inflammatory response
- Depression can contribute to neuropsychological impairment or exacerbate cognitive deterioration caused by normal aging in HIV-infected adults (Gibbie et al., 2006), manifested by:
  - Decrements in functional ability (Activities of Daily Living)
  - Difficulty with adherence to antiretroviral therapy and other medical treatments
ROAH: Prior History of Depression

No: 48.1%
Yes: 51.9%
Depression Assessment in ROAH

- Depressive symptomatology measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977)
- CES-D: 20-item self-report scale referring to symptoms experienced in the previous week; 4 items are reverse coded to prevent response-bias
- Responses scored on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time)
- Items are summed to obtain a total score with range of 0 to 60; higher scores indicate greater level of depressive symptoms (α = .90 for ROAH sample)
ROAH: Symptoms of Depression

CES-D Scores

- Over 2/3 are Moderate to Severely Depressed
- 0 to 15
  - 37%
- 16 to 21
  - 20%
- 22 or More
  - 43%

Over 2/3 are Moderate to Severely Depressed
Figure 2  Comparison of Average CES-D Scores among Middle-age and Older Adults who are Community-dwelling, Visually-Impaired, or Living with HIV in ROAH. Data on Community-dwelling adults and visually impaired adults were obtained from Gump et al. (2005) and Horowitz et al. (2006), respectively.
CES-D: Level of Depression Symptoms
Health Factors Contributing to Depression for PLWH

- **PRIOR HISTORY**: major depressive disorder or significant depressive symptomatology (Harlow et al., 1991; Lyness et al., 1999; Mueller et al., 2004)

- **COMORBID PSYCHIATRIC DISORDER**: e.g., anxiety disorders, bipolar disorders, post-traumatic stress disorder (PTSD), and substance use (Pence et al., 2006; Rabkin et al., 2000; Leserman et al., 2005).

- **PHYSICAL HEALTH**: HIV symptoms, number of comorbid conditions, health-related functioning (Tostes et al., 2004; Tsao et al., 2004)
Psychosocial Factors Contributing to Depression for PLWH

- **CHRONIC STRESS:** adverse life circumstances (e.g., poverty, employment, housing, caregiving responsibilities, health care access, crime, substance use (Gurung et al., 2004; Jones et al., 2003)

- **HISTORY OF TRAUMA/ABUSE** (e.g. sexual abuse, physical abuse, or both; childhood physical neglect; childhood emotional neglect; Leserman et al., 2005)

- **HIV STIGMA:** present regardless of age, gender, or sexual orientation, and particularly demoralizing among persons who have contracted HIV but are not a member of a high-risk group (e.g., women; Stanley, 1999).
Additional Psychosocial Factors & Depression

- **LONELINESS**: among older adults with HIV, increased loneliness has been associated with higher levels of depression (Vance, 2006)

- **SOCIAL ISOLATION**: a diagnosis of HIV can also lead to social isolation due to:
  - Self-isolation for self-protection (Emlet, 2006)
  - Rejection from members of the social network due to HIV diagnosis or because of other behaviors associated with HIV infection (e.g., IV drug use, homosexuality; Flowers et al., 2006; Lichtenstein et al., 2002; Mayers & Svartberg, 2001; Trzynka & Erlen, 2004)
Predictors of CES-D Scores Among Older Women with HIV: Health & Psychosocial Stressors

Cumulative $R^2 = .48$, $p < .001$

$N = 264$
Figure 1 Comparison of UCLA Loneliness Scale Scores between Older Adults with HIV and Community Dwelling Elderly as reported in Adams et al. (2004).
ROAH: Loneliness and Social Network Type

UCLA Loneliness Scores

- Integrated
- Friend-Centered
- Isolated

Scores:
- 36
- 38
- 40
- 42
- 44
- 46
- 48
Implications of ROAH Study

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
Loneliness and HIV-Related Stigma Explain Depression Among Older HIV-positive Adults (in press)

Grov, Golub, Parsons, Brennan, Karpiak

Center for HIV/AIDS Educational Studies and Training (CHEST) and AIDS Community Research Initiative of America (ACRIA)
ACRIA Study Using the MacArthur Model as an Intervention for Depression

Marlena Vega, PhD
Study Clinician

Funded by the Robert Mapplethorpe and Keith Haring Foundations
ACRIA Study Using the MacArthur Model Intervention for Depression

- Patients screened for depression using the PHQ-9
- Positive screens referred to primary care/psychiatrist for evaluation
- Confirmed cases of depression receive treatment as usual (i.e., medication, individual therapy and/or group therapy)
- Care Manager (mental health clinician) makes weekly telephone calls to support patients in treatment
  - Call is simple: “Hi, How are you” etc…. 
  - Periodic rescreen with PHQ-9 to assess treatment progress 
  - Problems that emerge during call are referred to mental health provider
Interim Follow-up Results

- Change in CES-D Scores Over 20 Weeks; All weeks significantly lower than baseline
Targeting Older Adults

- ACRIA is the first agency to develop comprehensive materials targeting older adults.

- Trainings have been developed to target those who provide services to older adults, as well ASO staff.

Contact Luis Scaccabarozzi (LScaccabarozzi@acria.org)
Director ACRIA  HIV Health Literacy Program (HHLIP)
ACRIA’s HIV Older Adults Booklet

older adults and HIV

ancianos y VIH
The Greying of HIV

Today 70% of NYC residents living with HIV/AIDS are over 40 and 32% are over age 50.

FREE TRAINING for Social Service and Healthcare Practitioners, and Peer Educators

This growing population of older adults with HIV is often isolated and depressed, facing the unique stresses of HIV stigma and ageism. As they age they may be cut off from the services they need. Older adults rarely hear about HIV, and even more rarely about how they can protect themselves.

The AIDS Community Research Initiative of America (ACRIA) and the Council of Senior Centers and Services (CSCS) are offering a citywide HIV training program funded by the New York City Council. These free trainings will help social service providers address HIV prevention issues and understand better the needs of older adults.

For info: Karol Mac Council of (312) 398-3060

HIV doesn’t care how old you are...

More than 2 out of 3 people living with HIV in NYC are over 40, and 1 in 3 are over age 50.

Think you’re too old for HIV?

Think again.

One in every six new cases in NYC is found in people over 50.

Some say HIV’s only for young folks.

You’ve lived too long to believe that nonsense.

Get tested for HIV.
ROAH Collaborative Efforts Include:

- Center for HIV Educational Studies and Training (CHEST)
- NYU School of Nursing
- Fordham University, Dept. of Economics
- Syracuse University, Dept. of Sociology
- Columbia University School of Social Work
- University of Alabama
- Chelsea Westminster Hospital, London UK (Dr. Youle)
- American Academy of HIV Physicians
- University of Ohio at Miami
- American Geriatrics Society
There are multiple publications/abstracts/chapters published, in press and submitted based on the ROAH data set.

Contact Dr Stephen Karpiak at skarpiak@acria.org for detailed information or any inquiries