The Emerging Population of Older Adults with HIV

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AIDS Community Research Initiative of America (ACRIA)
ACRIA Center on HIV and Aging
New York, New York
ACRIA: AIDS Community Research Initiative of America
founded 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

HIV Health Literacy & Training/TA/Capacity Building
• Training/TA/CBA for orgs across the U.S. using a unique, tailored, case management approach
• Dozens of curriculum modules, including nearly 30 on older adults
• Offer continuing education credits
• Materials in several languages
An Aging Population

GROWTH OF THE 50+ POPULATION 1900-2040

Aging “Baby Boomers” + Increased Longevity = AGE EXPLOSION
Boomers will be living longer:
% people age 65 who will live to age 90

Source of data: US Census Bureau
U.S. AIDS Cases Over Age 50 (CDC)

Year | Cases
--- | ---
2000 | 75000
2007 | 280000
Impact of HAART

Source: NYC Dept of Health & Mental Hygiene, 2004
Median Age at Death due to HIV Disease
United States, 1987-2006

Note: For comparison with data for 1999 and later years, data for 1987–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.
New York City remains U.S. HIV Epicenter

Approximately

120,750

known people living with the HIV in New York City
2010 NYC HIV Epidemiology

40 % of people with HIV/AIDS in NYC are Over 50

74 % of people with HIV/AIDS in NYC are Over 40
Florida HIV/AIDS Cases 2006

Total = 69,832

32% Over 50
76% Over 40
San Francisco HIV/AIDS Cases
SF Dept of Health, 2008

Total cases: 15,757

40% Over 50
80% Over 40
Los Angeles AIDS Cases 2007

Total cases: 22,455

33% Over 50

77% Over 40
The CDC predicts that by 2015

50%

of all people living with HIV
In the U.S.
will be over age 50
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-reviewed and published articles.


WHO

Are These Older Adults Living with HIV/AIDS?
Research on Older Adults with HIV
**Older Adults with HIV:**
An In-depth Examination of an Emerging Population

M. Brennan, S. E. Karpiak, R. A. Shippy & M. H. Cantor


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

Participants:
(N = 914)
NYC community-dwelling, HIV-positive adults over 50

Procedures:
Participants completed a self-administered survey after giving
informed consent

HIPAA Compliant and IRB-Approved

ROAH Study Design
ROAH Modules

Module 1: Demographic Profile
Module 2: HIV Status/Health
Module 3: Sexual Behavior
Module 4: Substance Use
Module 5: Psychological Distress/Depression
Module 6: Social Networks
Module 7: Psychological Well-being & Health-related Quality of Life
Module 8: Disclosure & Stigma
Module 9: Spirituality & Religiousness
Demographics
NYC HIV Epidemiology

Male 69%
Female 31%

Black 44%
Latino 32%
White 21%
API / Am. Indian 3%
ROAH: Age Distribution

Mean Age = 55.3 / Age range was 50-78

Age Group

52% 60-64
30% 65-69
12% 70-74
6% 75+
ROAH: Sexual Self-Identification

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

### Employment Status

<table>
<thead>
<tr>
<th>Status</th>
<th>%</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>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S.</td>
<td>83.5</td>
</tr>
<tr>
<td>Other nation</td>
<td>6.5</td>
</tr>
</tbody>
</table>

### Education

<table>
<thead>
<tr>
<th>Level</th>
<th>%</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>
ROAH: Proportion with AIDS Diagnosis

- White: 68%
- Black: 46%
- Latino: 52%
ROAH: HIV Treatment

Currently Taking ARVs %

- Black 87.3
- Latino 84.8
- White 85.3

- Male 86.0
- Female 83.0
ROAH: HIV Providers

Treatment facility

- **Private physician**: 21.9%
- **Public clinic / hospital**: 58.7%
- **VA hospital**: 4.9%
- **ASO / day program**: 17.0%

83% of ROAH participants are Medicaid-dependent
ROAH: Years since HIV Dx

- Male 13.1
- Female 11.4
- White 14.9
- Black 11.8
- Latino 12.9
ROAH: Years Since HIV Diagnosis by Sexual Orientation/Identity

- Heterosexual: 12.0
- LGBT: 13.7
ROAH: Living Arrangement

- Alone: 70%
- With Partner or Spouse: 14%
- With Others: 16%
Proportion Living Alone: ROAH vs. Community-Dwelling NYC Elderly

NYC Elderly 65+

ROAH

0% 10% 20% 30% 40% 50% 60% 70% 80%

39% 70%
ROAH: Mode of Transmission
The Changing HIV Population

Unprotected Vaginal
Sharing Needles
Unprotected Anal

> 10 years
6-10 years
1-5 years
Stigma
ROAH: Disclosure of HIV Status (%)
ROAH: Reluctance to disclose

- Line: 43%
- Axon: 38%
- White: 30%
Comorbidities in ROAH

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

- Elderly 70+: 1.1
- ROAH: 3.3
Substance Use
### ROAH: Tobacco Use

<table>
<thead>
<tr>
<th></th>
<th>Current</th>
<th>History</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>57 %</td>
<td>84 %</td>
</tr>
</tbody>
</table>
## ROAH: Substance Use Recovery

<table>
<thead>
<tr>
<th>Recovery Status</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
ROAH: Social Networks

CAREGIVERS
are derived from
SOCIAL NETWORKS

Social networks are a significant healthcare resource equal to $400$ billion
ROAH: Informal Network Composition

<table>
<thead>
<tr>
<th>Relation</th>
<th>Living</th>
<th>Functional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>41.2</td>
<td>27.2</td>
</tr>
<tr>
<td>Child</td>
<td>54</td>
<td>37.7</td>
</tr>
<tr>
<td>Sibling</td>
<td>78.7</td>
<td>43.8</td>
</tr>
<tr>
<td>Other Relative</td>
<td>50.4</td>
<td>31.4</td>
</tr>
<tr>
<td>Friend</td>
<td>66.1</td>
<td>69.4</td>
</tr>
</tbody>
</table>
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: UCLA Loneliness Scores by Social Network Type

- Isolated: 47.6
- Friend-Centered: 43.2
- Integrated: 41.1

Scores range from 36 to 48.
ROAH: Sexual Behavior

Center for HIV/AIDS Educational Studies and Training (CHEST)
Hunter College,
City University of New York
ROAH: Prevention for Positives

Do you receive HIV prevention information?

No 1 %   Yes 99 %

Does prevention information target older adults?

No 57 %   Yes 43 %
Concurrent HIV/AIDS among Persons Diagnosed with HIV in 2006 by Age, U. S.

Figure 3  Unprotected Sex and Serosorting among Older Adults with HIV
ROAH: First Data on Risk Behavior in Older Adults

- 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

- Can suppress immune responses (e.g., Tiemeier, van Tuijl, Hofman, Kiliaan, & Breteler, 2003)
- Is associated with an increased inflammatory response (Kiecolt-Glaser & Glaser, 2002)
- Contributes to neuropsychological impairment or exacerbates cognitive deterioration caused by normal aging in HIV-infected adults (Gibbie et al., 2006):
  - Decrements in functional ability (Activities of Daily Living)
  - Difficulty with adherence to HAART and other treatments
ROAH: Prior History of Depression

- Yes: 51.9%
- No: 48.1%
ROAH: CES-D Symptoms of Depression

Severe (23+)
43%

Moderate
(16-22)
20%

Not Depressed
(1 to 15)
37%
ROAH: Group Differences in CES-D Scores

<table>
<thead>
<tr>
<th></th>
<th>Women</th>
<th>Men</th>
<th>Black</th>
<th>White</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>20.1</td>
<td>19.9</td>
<td>18.9</td>
<td>20.8</td>
<td>21.3</td>
</tr>
</tbody>
</table>
ROAH: Collaborative Efforts

- Center for HIV Educational Studies and Training, Hunter College, City University of New York
- New York University, College of Nursing
- Fordham University, Department of Economics
- Syracuse University, Department of Sociology
- Columbia University, School of Social Work
- University of Alabama
- Chelsea Westminster Hospital, London, UK
- Terrence Higgins Trust, London, UK
- American Academy of HIV Medicine
- University of Ohio at Miami
- American Geriatrics Society
- Center on Halstead, Chicago
Implementing Community PROMISE with Older Adults at Risk for HIV & Older Adults Living with HIV

Developing a Comprehensive Prevention Effort
Prevention Challenges: 50+

- Persons 50+ have many of the same risk factors for contracting HIV that younger people have.

- Many older people are sexually active but may not be practicing safer sex to reduce their HIV risk.

- Older women are especially at risk because age-related vaginal thinning and dryness can cause tears in the vaginal area.
• Some older persons inject drugs or smoke crack cocaine, which can put them at risk for HIV infection. HIV transmission through injection drug use accounts for more than 16% of AIDS cases among persons aged 50 and older.

• Some older people, compared with younger people, may be less knowledgeable about HIV/AIDS and therefore less likely to protect themselves.

• Many do not perceive themselves as at risk for HIV, do not use condoms, and do not get tested for HIV.
Prevention Challenges: 50+ (3)

- Older people of minority races/ethnicities: discrimination and stigma that can lead to later testing, diagnosis, and reluctance to seek services.

- Health care professionals may underestimate their older patients’ risk for HIV/AIDS & may miss opportunities to deliver prevention messages, offer HIV testing which delays care.

- Physicians may miss a diagnosis of AIDS because some symptoms can mimic those of normal aging, for example, fatigue, weight loss, and mental confusion.

- The stigma of HIV/AIDS may be more severe among older persons, leading them to hide their diagnosis from family & friends. Failure to disclose HIV infection may limit or preclude potential emotional and practical support.
HIV & Older Adults Initiative...
NYC HIV & Aging Initiative: Year 1 Objectives

- Develop a citywide prevention and HIV health literacy program targeting senior services, healthcare providers & older adult peer educators

- Deliver vital information on HIV to senior services providers on the unique needs of older adults living with HIV/AIDS

- Reduce HIV myths, discrimination and stigma among seniors and their providers

- Promote collaborations among HIV/AIDS service providers, senior services providers, and healthcare providers
NYC Older Adults Initiative: Year 1 Accomplishments

Provided HIV prevention, care, treatment & stigma training to senior services provider staff & identified key peers at organizations serving older adults in all 51 City Council Districts in New York:

- Nearly 1700 service providers & key peers participated
- Approximately 30% of trainings in Spanish
NYC Older Adults Initiative: Year 1 Accomplishments

Development & distribution of educational and social marketing materials in a variety of formats:
- Tri-folds
- Booklets
- DVDs
- PSAs
- 13 curriculum modules
- Facilitator's Guide

All materials were developed in both English & Spanish
HIV & Older Adults Initiative Palm Cards:
Training Marketing Materials

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.

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.
HIV & Older Adults Initiative Palm Cards: Training Marketing Materials

Think you’re too old for HIV?
Think again.
One in every six new cases in NYC is found in people over 50.

¿Piensa que tiene demasiada edad para el VIH?
Piense se nuevo.
Uno de cada seis nuevos casos en la Ciudad de Nueva York tiene más de 50.
HIV & Older Adults Initiative Palm Cards:
Training Marketing Materials

Las personas mayores también pueden tener VIH....

Algunos dicen que el VIH solo afecta a los jóvenes

Ya ha vivido lo suficiente para creerse eso

Hágase la prueba del VIH

Some say HIV’s only for young folks.

You’ve lived too long to believe that nonsense.

Get tested for HIV.

Some say HIV’s only for young folks.

You’ve lived too long to believe that nonsense.

Get tested for HIV.
Detenga el SIDA.

Stop HIV/AIDS

SOBRE EL VIH?

Learn It. Fight It. Defeat It.

Knowledge Stops AIDS

Para Detener el SIDA

Isn't It About Time You Knew...

The Truth About HIV


Su Comunidad Necesita de su Sabiduría

¿No es hora de que conozca la verdad

Funded in whole by the New York City Department of Health and Mental Hygiene
First Booklet Aimed at HIV+ Older Adults

older adults and HIV

ancianos y VIH
First HIV Prevention Booklet Aimed at Older Adults
NYC Older Adults Initiative: Year 2 Accomplishments

- **New Training Modules:**
  - HIV, Domestic Violence & Older Adults
  - HIV, Older Adults & Health Literacy
  - HIV, Older Adults & Mental Health
  - HIV, Older Adults & Comorbidities
  - Community PROMISE: Implementing DEBIs in OA Communities

- **Training/Capacity Building/Technical Assistance**
  - 148 days of training and services for staff/key peers at 40 senior services organizations in high HIV prevalence areas
  - 4,264 participants in Year 2!
NYC Older Adults Initiative: Year 2 Accomplishments

Materials/Social Marketing

- Translation & Reproduction: 1,000 copies of three trifolds into **Russian, Chinese and Haitian Creole**

- Developed & Distributed 1,000 toolkits with HIV/Older Adults curriculum & resources

- Develop & Distribute 5,000 copies of HIV & Aging Services Resource Directory
NYC Older Adults Initiative: Year 2 Accomplishments

- **DVD Discussion Guides**
  - Two discussion guides were developed in English & Spanish to accompany the DVDs to make integrating them easier for service providers.
NYC Older Adults Initiative: Year 2 Objectives

Community PROMISE

- CDC Evidence Based Intervention
  (Community Level Intervention)

- Peers Reaching Out and Modeling Intervention Strategies for HIV/AIDS Risk Reduction in their Community

- Tailoring and implementing CDC DEBI: Community PROMISE for Older Adult populations (50+)
ACRIA chose to implement Community PROMISE within the over 50 target population because:

- DEBI’s had not been previously implemented in an older adult target population
- PROMISE allowed to target the highest risk groups in NYC (MSM & Women of Color over 50 in HIA)
- Felt OA would be more inclined to engage in behavior change based on messages which resonate with them via relevant RMS.

Community PROMISE
Having face to face discussion with peer advocates could initiate a level of trust which could encourage behavior change among OA.

The direct impact of the RMS as well as the potential indirect impact when people share the stories with others within their cohort – these types of relatable materials with OA faces barely exist.
Rhonda
My name is Rhonda. I'm 58 and the mother of two beautiful teens. I've lived in Brooklyn for almost all my life. It's here that I got married and started a family.

Clara
My name is Clara. I have three adult children and eight grandkids. I got married to my childhood sweetheart at 17 and was with only him for 47 years. I think I look great for my age – people usually don't believe I'm 67.
Role Model Stories (year 1)

Nelly
My name is Nelly. I'm 63 years old and have lived in Brooklyn since I was a small girl. About ten years ago, I found my husband passed out in the kitchen with a needle in his arm.

Felipe
My name is Felipe, but people call me “Negrito.” I'm 59 years old and was born in Venezuela. I managed to get across the U.S. border with help from friends. I was 29 at the time and knew I was breaking the law, but I had to get away from everything that was going on in my country.
Marcel
My name is Marcel and I’m 67. I moved to Brooklyn from South Carolina when I was in my twenties. Back then I was reckless and didn’t think about my health much. Condoms and HIV were just not a part of my life.

Brenda
My name is Brenda. I’m a 59-year-old grandmother living in Harlem. Some years ago, I met a man who I thought was wonderful. We were both doing drugs – in fact that’s how we met.
Gwendolyn

My name is Gwendolyn. I’m a 50-year-old transgender woman. I live in Brooklyn on Eastern Parkway, right across from the Lubavitch Hasidic synagogue. I’m single but I keep myself busy, and I date a lot. I have dates almost every day of the week. Being monogamous is not for me – life is short and I want to enjoy it!

A couple of weeks ago I noticed a small sore in my groin. I thought it was an insect bite, so I didn’t do anything. I don’t know when or how it happened, but it went away. Then, two days ago I woke up with a very strange rash on the palms of my hands. I didn’t know what to think.

I decided to go to the City Health Department on Flatbush Avenue to get a checkup. I almost fainted when they told me I had syphilis! I was treated right away, but I was scared to learn that the same things I did that led to my getting syphilis could also put me at risk for HIV.

I love the guys I date but my health comes first. I think it’s time I slow down and take things more carefully. I think I should have fewer dates and try to use condoms. I don’t want to get sick again – life is short, but it may be shorter if I get sick.
Patricia
My name is Patricia and I’m 56 years old. My family is from Puerto Rico but I was born here in the Bronx. I live on the Grand Concourse near Yankee Stadium, a few doors down from St. Raymond’s Church. That’s where I go to talk to my priest when I feel confused or scared about something.

A few weeks ago after Mass, I met Manuel. He’s very handsome and we’ve been dating. I really enjoy his company and the sex is great. But he doesn’t like to wear condoms. At my age, it’s hard to date so I don’t want to spoil the moment – or the relationship.

At my last GYN appointment at Bronx Lebanon hospital, my doctor asked me if I was having sex. I said yes, and to my surprise he asked if we used condoms. I told him we didn’t – I know Manuel is healthy, and besides, he hates them. My doctor gave me some pamphlets about HIV and older adults that included information about female condoms.

After reading them I was surprised to learn that women after menopause may have a higher risk for HIV! And to be honest, I never asked Manuel about who else he’s been with. We need to talk about that before we think about having sex without a condom again.
The peers told us where to distribute rather than us telling them – they had the information on where the target population congregates.

- Areas mentioned in the stories (i.e. near hospitals, intersections, subway stations, etc.)
- Barbershops & beauty salons
- Gay Bars
- Senior Centers (lunch time)
Lessons Learned...

- Most older adult service agencies do not provide adequate services to the high risk 50-65 year old group.

- Participants identified a need for more targeted primary and secondary prevention messages/materials.

- Agencies that provide services to older adults are not convinced that those with HIV should use their services.
Lessons Learned

- Aging Services Organizations are largely unaware of the aging HIV population
- Significant cultural barriers between HIV and Aging services are barriers to needed collaboration
- HIV stigma is significant in staff & clients at senior serving centers
ACRIA Center on HIV and Aging

GOALS: Education and Training Programs

Target
- older adults and HIV services providers

Partner
- with organizations serving older adults, among others

Support
- networking and collaboration among HIV service providers and organizations serving older adults

Improve
- HIV knowledge and change attitudes and beliefs among those serving older adults
If you’d like more information on HIV & Aging initiatives at ACRIA:

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