

3rd Annual Iris House Summit on Women Living with HIV/AIDS

Thursday, June 12, 2008

# **HIV & Aging**

## **Is it Aging or is it HIV?**

Stephen Karpiak, PhD

Associate Director for Research

AIDS Community Research Initiative of America

New York City

# ACRIA History

## Founded in 1991 as CRIA Community Research Initiative on AIDS

The agency has been a site for clinical trials for HIV from 1992 through today. Every class of anti-retroviral has been tested at the agency.

In 1997 CRIA launched a comprehensive treatment education program. This has evolved into its present Health Literacy Program.

In 2001, expanding into national work, the agency became ACRIA (AIDS Community Research Initiative of America).

# ACRIA's Quarterly UPDATE



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fall  
2005

## HIV on the Inside

As the contributors to this issue of *ACRIA Update* make clear, the twin epidemics of HIV and HCV continue to seriously impact the health and well-being of prisoners across the U.S. For those who have never been incarcerated, it is all too easy to ignore the epidemic that is raging behind the bars of this country's prison system. But with a quarter of all people with HIV receiving their care while in prison, any attempt to address the HIV epidemic must look seriously at the quality of care, and the quality of life, of people living "on the inside."

Unlike any previous issue of *ACRIA Update*, we found when contacting writers that many felt constrained in their ability to

speak out against problems in the prison system. Whether they feared losing funding or were reluctant to criticize their employers, more than one author we approached did not feel they could write a piece that told the unvarnished truth about HIV in prison.

Likewise, many prisoners were unable to speak honestly, for fear of reprisals from both the correctional system and other inmates. We applaud those who did contribute and who even asked us to sign their name in spite of the consequences of such outspokenness. We can only hope their courage is met by an equal commitment from those of us "on the outside."

Mark Milano

## Prison Health = Public Health:

### HIV Care in New York State Prisons

by Romeo Sánchez

"The degree of civilization in a society can be judged by entering its prisons." – Fyodor Dostoevsky

There is a public health emergency in New York State prisons. Infection rates of HIV and hepatitis C virus (HCV) are 8 to 10 times higher in prison than in the general community. Women are disproportionately affected by both diseases. The most recent NYS Department of Health (DOH) blinded seroprevalence studies found HIV infection present in 5% of men and 14% of women. HCV infection rates are 14% for men and 23% for women. The NYS Department of Correctional Services (DOCS) estimates that there are approximately 10,000 prisoners with HCV – but this is very likely an underestimate. Published studies of pris-

oners in the correctional systems of California, Texas and Maryland have found that 30-40% of prisoners test positive for HCV. Since NYS DOCS currently houses about 65,000 prisoners, this indicates a probability of under-reporting.

There are 70 prisons in New York State, and the health care provided at each facility is subject to oversight only by DOCS, with no effective review by any outside agency. Whether a prisoner receives adequate care is dependent upon whether he or she is lucky enough to be at a facility where the generally understaffed and often poorly

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verano  
2007

## Más Allá de los Condones: Prevención del VIH

En esta última década, desde la aparición de la terapia combinada contra el VIH, hemos tenido grandes logros en el tratamiento del VIH. Los regímenes de medicamentos se han ido simplificando y se ha reducido la cantidad de pastillas a tomar. Tratamientos efectivos para los efectos secundarios nos han acercado al objetivo de hacer del VIH "una enfermedad crónica manejable." Las personas que viven con el VIH hoy en día pueden esperar vivir vidas más largas y saludables, comparadas a la época del inicio de la epidemia.

Pero los tratamientos no son la única respuesta. Para comenzar, los medicamentos usados para tratar el VIH son extremadamente caros, sobretodo en países desarrollados. En los Estados Unidos, a pesar de las ventajas económicas, el costo de proveer de medicamentos sobrepasa las posibilidades del gobierno, forzando a las personas a ponerse en listas de espera para obtener estas medicinas. Alrededor del mundo, la mayor parte de las personas que viven con el VIH no logran acceso a tratamientos efectivos, aun considerando los publicitados esfuerzos internacionales para expandir su acceso.

Existen otros problemas en tomar medicamentos antiretrovirales por el resto de la vida: Aunque la

situación ha mejorado, aún existen muchas personas que no pueden tolerar los efectos secundarios de algunos o todos los medicamentos en el mercado. La resistencia y la resistencia cruzada a los medicamentos son una preocupación creciente y nadie conoce la consecuencia o los efectos de uso prolongado de estos poderosos medicamentos.

El hecho es que no podemos únicamente usar los tratamientos para lograr deshacernos de esta epidemia. La prevención es esencial. Esta publicación intenta acercarnos a los aspectos actuales que rodean el tema de la prevención. Por el lado médico presentamos artículos sobre la búsqueda de vacunas y microbicidas efectivos y el uso de la profaxis de pre- y post- exposición. Además, varios perfiles examinan algunos de los temas más agudos sobre el comportamiento de riesgo, incluso aquellos que buscan el sexo sin usar el condón.

No debemos dejar que los avances en el tratamiento contra el VIH en los últimos diez años nos dejen satisfechos. La prevención, por último, sigue siendo la principal respuesta para erradicar esta epidemia y poder eliminar los costos asociados, e incluso el devastador costo de muchas vidas humanas.

Daniel Tietz, Editor en Jefe

## ¿Qué Pasó con la Vacuna?

por Richard Jefferys

Cuando el VIH fue descubierto a principios de los 80's, los científicos estaban optimistas de que una vacuna para prevenir la infección sería desarrollada en cuestión de años. Desafortunadamente, aquel optimismo fue perdiéndose y el VIH se convirtió en un enemigo complicado para los investigadores de una vacuna.

**El Enfoque de Anticuerpos Da en el Blanco**  
En la época del descubrimiento del VIH, se pensó que la mayor parte de las vacunas funcionaban al iniciar un tipo de respuesta inmunológica llamada respuesta de anticuerpo (ahora sabemos que las células T y otras partes del sistema inmunológico también participan). Los anticuerpos son pequeñas moléculas en forma de "Y" que son elaboradas por unas células del sistema inmune llamadas células B.

La función de los anticuerpos es la de flotar dentro del sistema circulatorio y envolver a los patógenos deshabilitándolos y marcándolos para su destrucción. Experimentos iniciales mostraron que el VIH reproducido en laboratorio, puede ser efectivamente bloqueado por los anticuerpos que se adhieren a la proteína externa del virus, llamada: proteína de la cobertura del VIH. Los científicos diseñaron vacunas basadas en una molécula en la cobertura llamada gp120, con la esperanza de que estas vacunas iniciaran la estimulación de la producción de anticuerpos similares, ofreciendo así una protección como si se hubiese expuesto al VIH.

Pero antes de que se desarrollaran estudios clínicos, los investigadores se dieron cuenta de que el VIH se adapta a vivir en una placa de laboratorio

(continúa en la página 3)



# ACRIA Publications

como comprender  
sus resultados del  
laboratorio

understanding  
your lab results

hepatitis viral  
y VIH

viral hepatitis  
and HIV

acria

acria

Asuntos de tratamiento  
para las mujeres

treatment issues  
for women

explicación de los  
estudios clínicos

clinical trials  
explained

acria

acria

control de los  
efectos secundarios

managing  
drug side effects

ancianos y VIH

older adults  
and HIV

acria

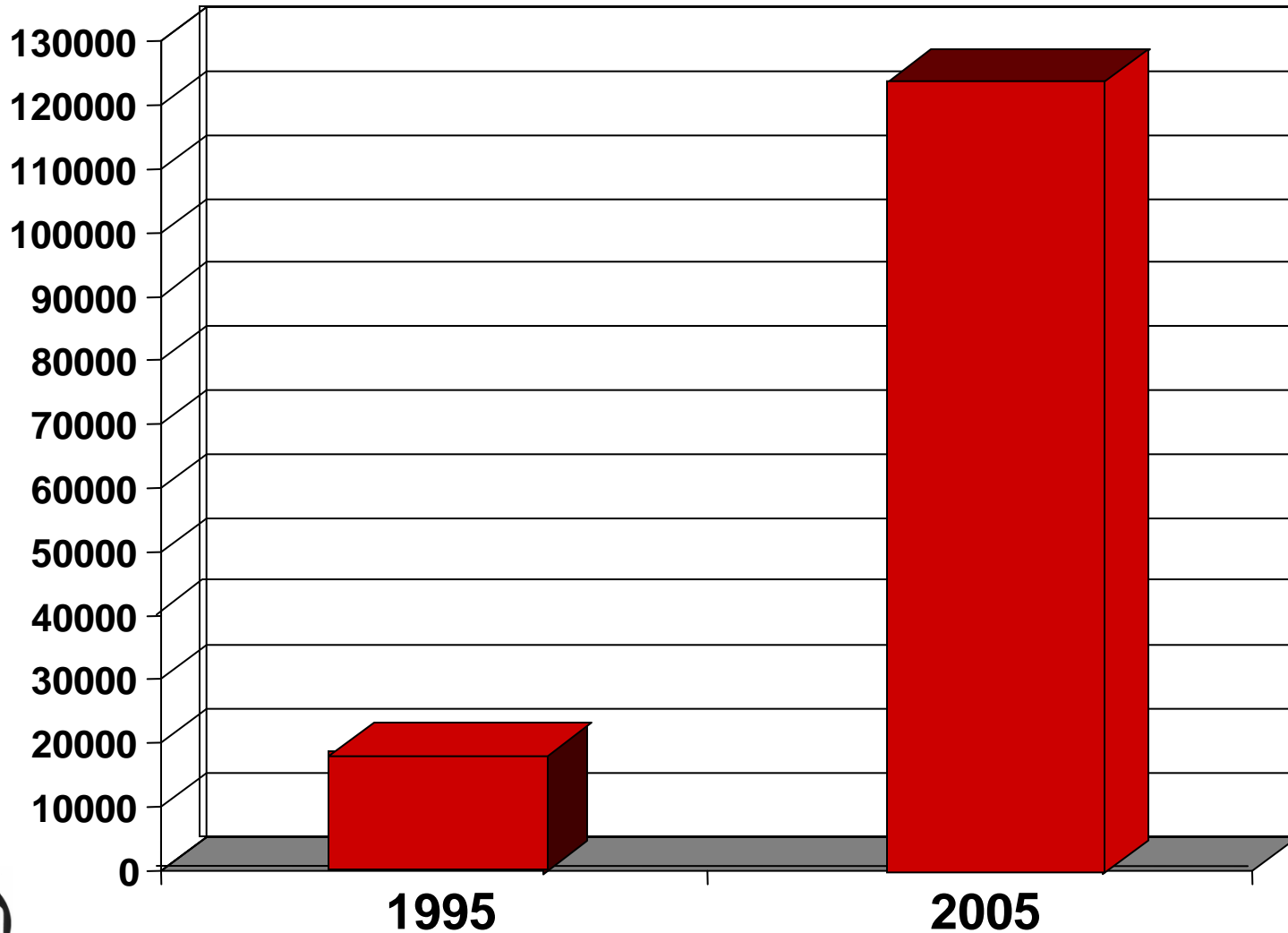
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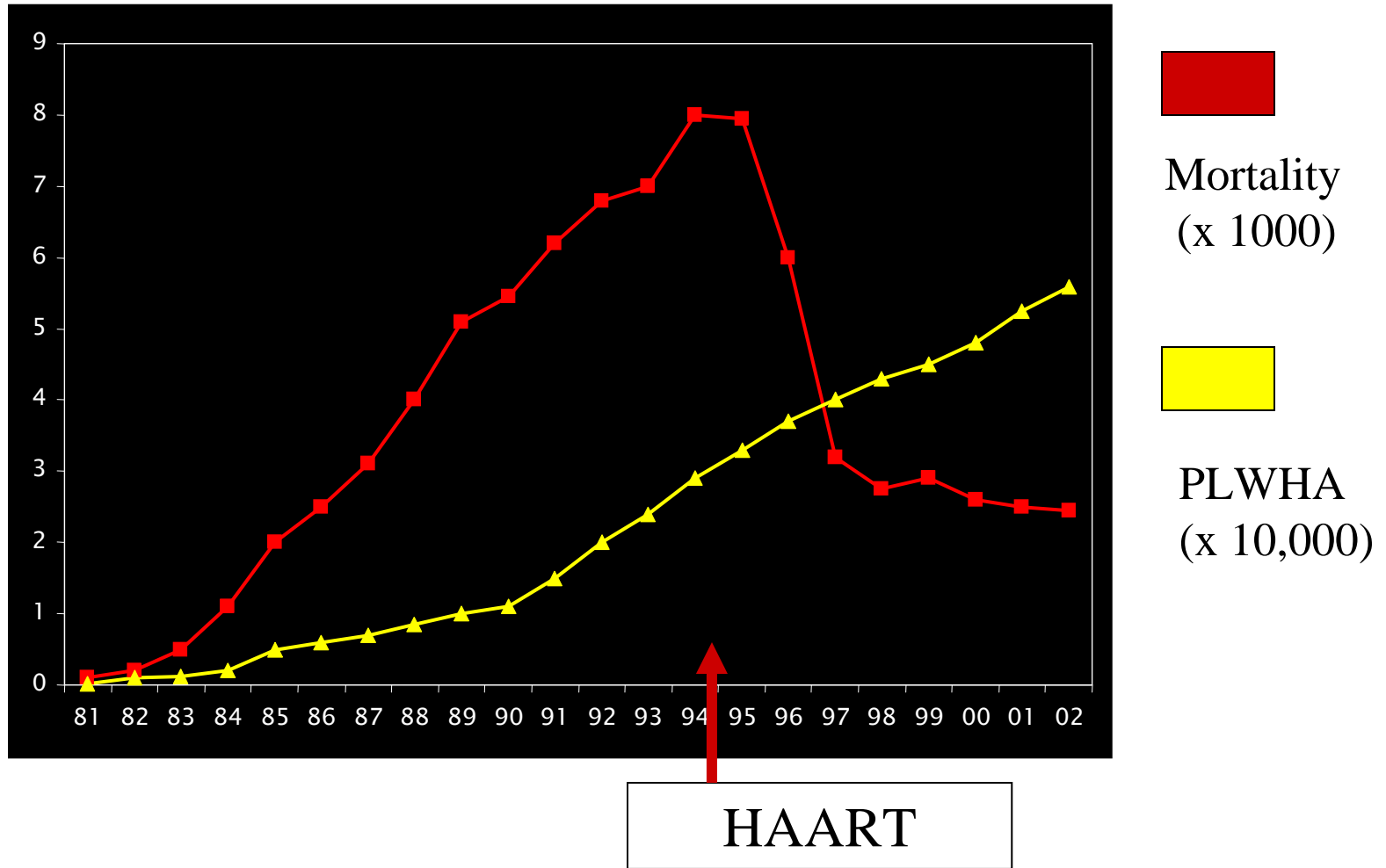
# Changes/Facts

- The number of new HIV infections in the United States each year remains stable at about 40,000 cases per year.
- Approximately 1.2 million people are living with HIV, 400,000 of them are living with an AIDS diagnosis.
- Treatments are allowing AIDS patients to live longer. The number of people living with AIDS continues to rise.
- This increase in HIV/AIDS prevalence means a growing burden on our prevention and treatment services. There are diminishing resources to take care of the growing aging HIV population

# USA AIDS Cases Over Age 50 - CDC



# Impact of HAART



# New York City is the USA HIV Epicenter

Today in NYC there are  
approximately  
**100,750**  
known people living with  
the HIV



# 2006 NYC HIV Epidemiology

(NYCDOH)

**34 %**

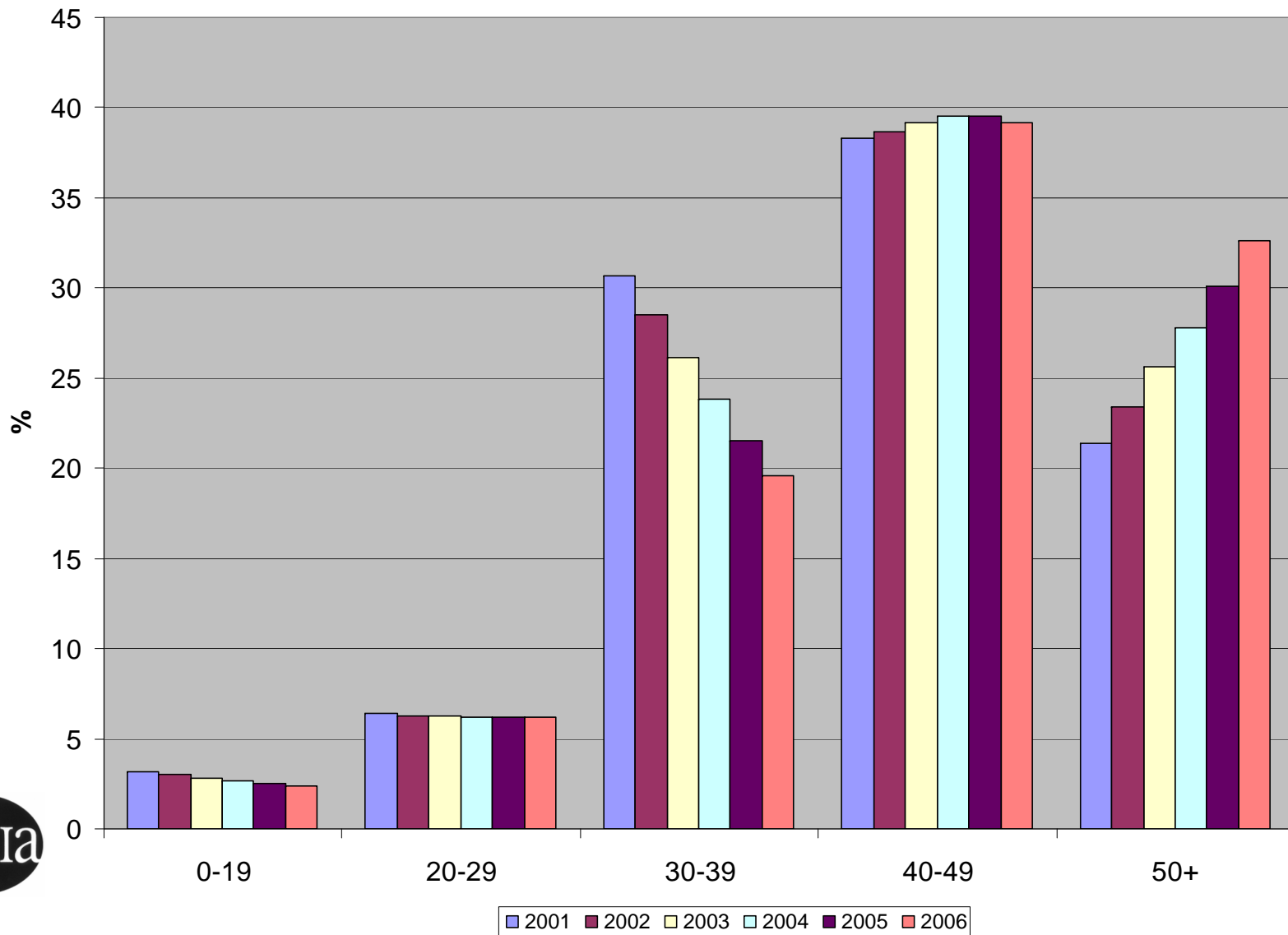
of people with HIV/AIDS in NYC are Over 50

**73 %**

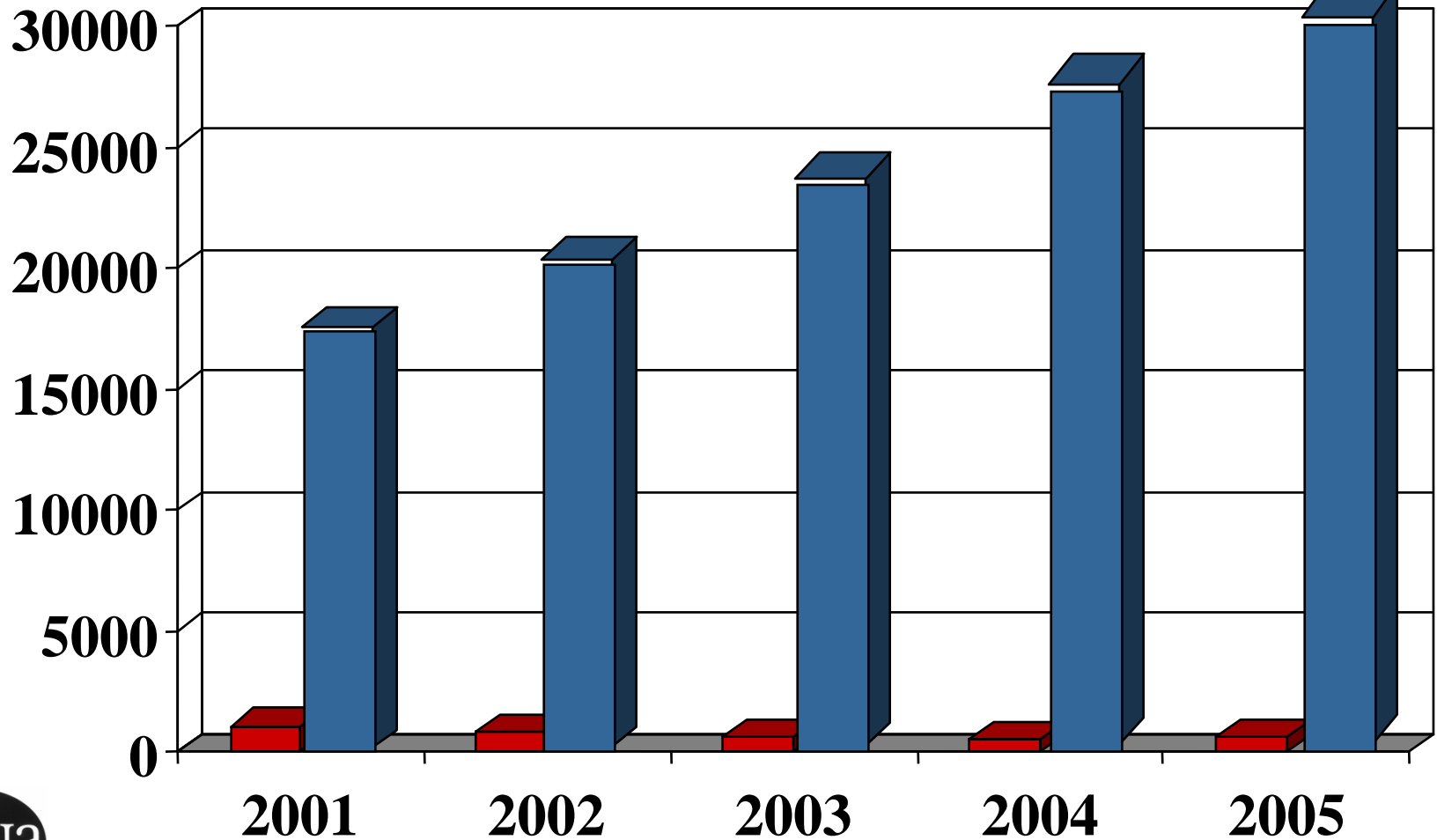
of people with HIV/AIDS in NYC are Over 40

# % People Living with HIV/AIDS in NYC by AGE

NYCDOH 2006



# The Aging of the HIV NYC Population (OVER 50)



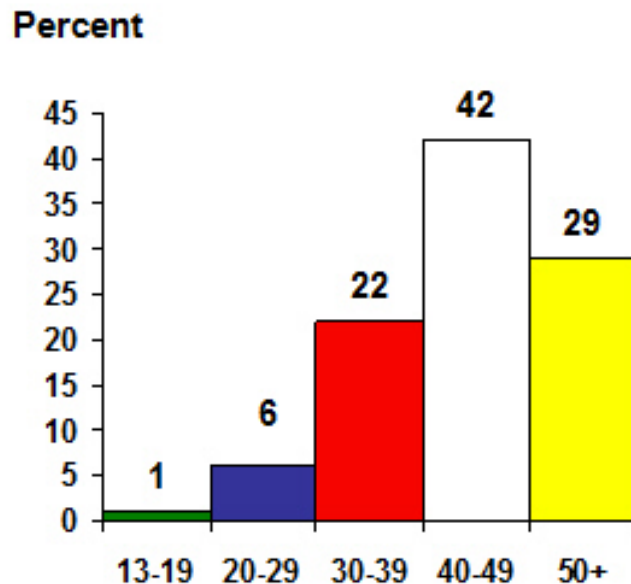
New York City is the Crystal Ball

**New York City is the Epicenter of the USA  
HIV/AIDS Epidemic**

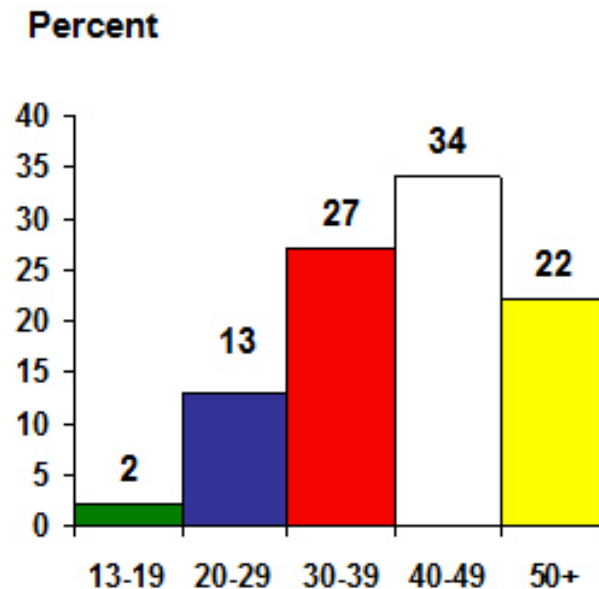
What Happens in NYC  
is happening throughout the USA.

## Percent of Living Adult HIV/AIDS Cases by Sex and Current Age Group Florida, Data through 2006

### Males (N=54,467)



### Females (N=25,365)



Comment: Females tend to be diagnosed with AIDS at a younger age than males, suggesting earlier onset of sexual activity and exposure to HIV, possibly through sex with older male partners. Data as of 04/05/07

# 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

- Shippy & Karpiak (2005). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health*, 9(3), 246-254.
- Shippy & Karpiak (2005). Perceptions of support among older adults with HIV. *Research on Aging*, 27(3), 290-306.



Yoni Brook for The New York Times

Patricia Shelton, 51, has lived with HIV for about 15 years.

## Facing Middle Age And AIDS

By DONALD G. McNEIL Jr.

With a jangle of bracelets, Patricia Shelton slid her chair in front of the air-conditioner in her daughter's apartment and fluttered her hands to cool her face.

"I swear, some days it's the menopause that gets me, not the H.I.V.,"

never really gets her. She has known she was infected since 1990, "the same time Magic Johnson announced to the world."

She is still on the two-drug regimen she started on, and her viral load is too low to be detected. But she leads workshops for older infected adults, and "I know I am very blessed," she said. "Some of them are on their fourth regimens, get bouts of PCP pneumonia, rashes, herpes, diarrhea."

In her 20's and 30's she was a

"closet heroin addict," keeping a Wall Street secretarial job, raising her children, not losing control. "A lot of us who had a past are happy housewives now, are mothers and grandmothers, are productive members of society," she said.

The infection lingers, but she has proved wrong the doctor who told her in 1990 that she had two years to live.

Although AIDS is thought of as a disease of the young, in the United States it is rapidly becoming one of the middle-aged and even the old. The number of Americans over age 50 infected with the virus that causes AIDS quintupled during the 1990's, "and a conservative estimate would be that there are more than 100,000 now," said Dr. Marcia G. Ory, a professor of public health at Texas A & M University and co-author of a 2003 report for the Centers for Disease Control and Prevention on AIDS in older Americans. Unless there is a new explosion of the disease among teenagers, demographers estimate, the majority of cases by the end of the decade will be in people over 50.

In New York City, the curve has moved even further. About 64 percent of the city's cases are over 40 right now, the New York City Department of Health said, and about 25 percent are over 50.

The medical and social ramifications of this shift are already becoming evident, particularly as the cost of care escalates.

"There will be some reality checking very soon," said Dr. Stephen Karpak, research director at the AIDS Community Research Initiative of America, or Acria, a nonprofit group based in New York that does surveys and clinical trials. "People are already being assigned to nursing homes at age 55. That gets very expensive."

In large part, the changing demographic of the disease is a testament to medical progress. Thanks to a

Continued on Page 6

R O A H



**R**esearch on **O**lder **A**dults with **H**<sub>IV</sub>

**Stephen E. Karpiak, PhD**

Director for Research  
Co-Principal Investigator  
ACRIA

**R. Andrew Shippy, PhD (c)**

Research Associate  
Co-Principal Investigator  
ACRIA

# ROAH Research Collaborators/Advisory Group

Chairperson: *Marjorie Cantor, Emerita Fordham U & Brookdale Scholar*

Stephen Bailous	Office of AIDS Policy, NYC DOH
J. Bookhardt-Murray, MD	Medical Director Harlem United & AIDS Institute NYS
David Dorfman, PhD	Mt. Sinai School of Medicine
Arlene Kochman, MSW	Yale University School of Medicine
Allen Matthews, Mardi Fritz	NYC DOH
Douglas Mendez, MD	Dominican Medical Association
Peter Nwakeze, PhD	NYC Association for HIV Over 50 and Hunter College
Jeffery Parsons, PhD	CHEST & Hunter College
Cynthia Poindexter, PhD	Fordham University Graduate School of Social Service
Bobbie Sackman, MSW	NYC Council of Senior Centers, Director of Public Policy
J. Edward Shaw	NYC Commission on AIDS
J. Lee Westmaas, PhD	SUNY, Dept of Psychology
Desieree Byrd, PhD	NeuroAIDS, Mt Sinai
Richard Havlik, MD	NIA/NIH Section Chief

# 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**

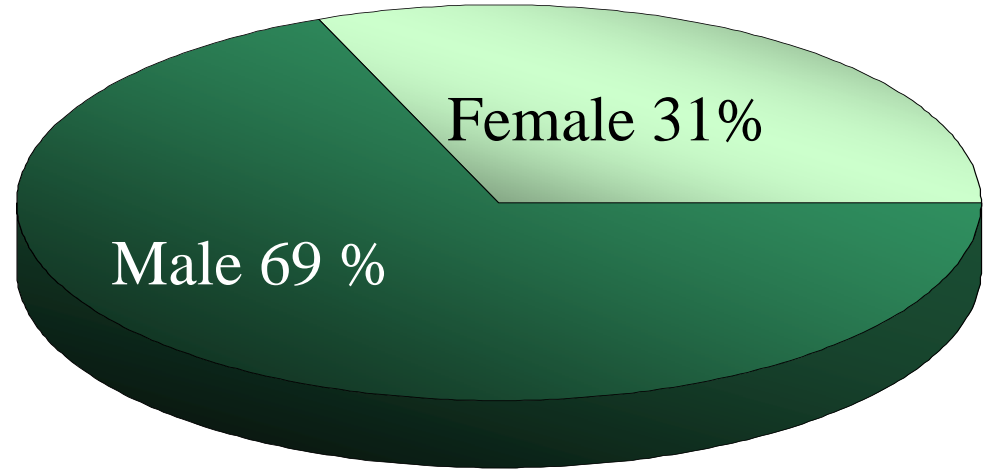
Participants completed a self-administered survey after giving informed consent

*HIPAA Compliant and IRB Approved*

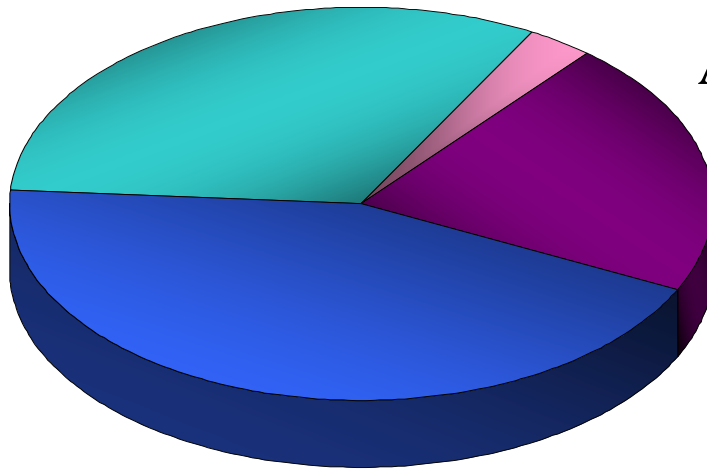
# ROAH Modules

- |                  |  |
|------------------|--|
| <b>Module 1:</b> | <b>Demographic Profile</b>   |
| <b>Module 2:</b> | <b>HIV Status/Health</b>   |
| <b>Module 3:</b> | <b>Sexual Behavior</b>   |
| <b>Module 4:</b> | <b>Substance Use</b>   |
| <b>Module 5:</b> | <b>Psychological Distress/Depression</b>                             |
| <b>Module 6:</b> | <b>Social Networks</b>   |
| <b>Module 7:</b> | <b>Psychological well-being &amp; health-related quality of life</b> |
| <b>Module 8:</b> | <b>Disclosure &amp; Stigma</b>                                       |
| <b>Module 9:</b> | <b>Spirituality &amp; Religiousness</b>                              |

# 2004 NYC HIV Epidemiology



Latino 32 %



API / Am. Indian 3 %

White 21 %

Black 44 %

# ROAH Demographics

## **Gender**

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■ Women	29.4
■ Men	70.6

## **Ethnicity**

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■ Caucasian	12.4
■ Black	50.2
■ Hispanic	33.5
■ API/Other	3.9

## **Education**

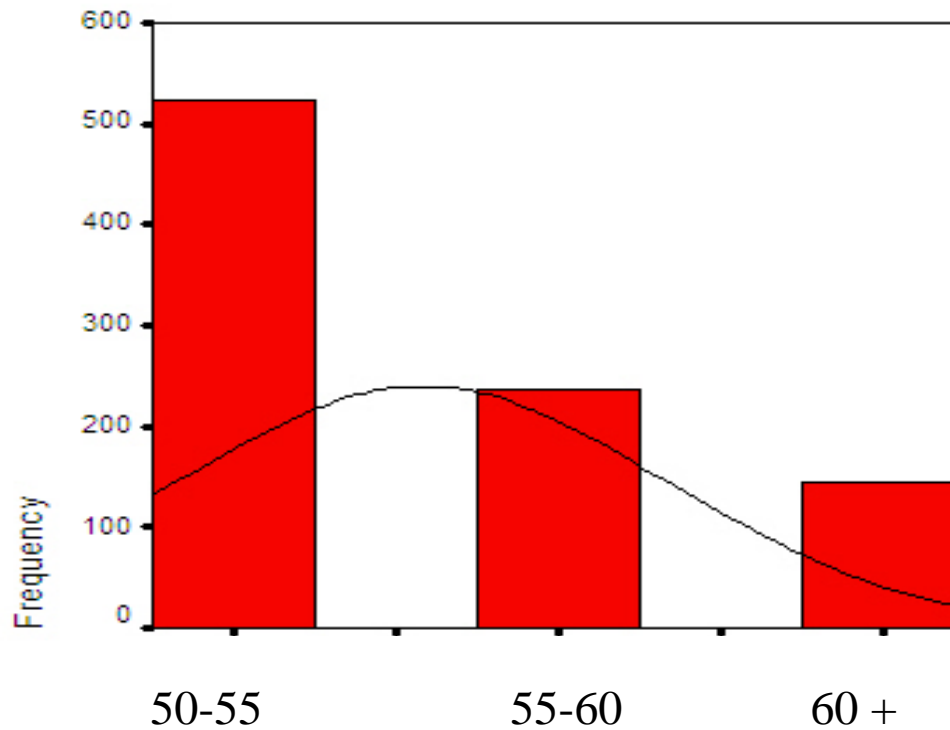
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■ Less than high school	20.4
■ High school graduate	58.6
■ College graduate	21.5

# ROAH: Age Distribution

Mean Age = 55.3

Age range was 50-78



# ROAH Demographics

<b>Living Arrangement</b>	<b>%</b>
▪ Alone	65.3
▪ With others	34.7

<b>Employment Status</b>	
▪ Working	8.3
▪ Retired	6.9
▪ Unemployed	20.1
▪ Disability	64.2

<b>Country of Birth</b>	
▪ USA	83.5
▪ Other nation	16.5



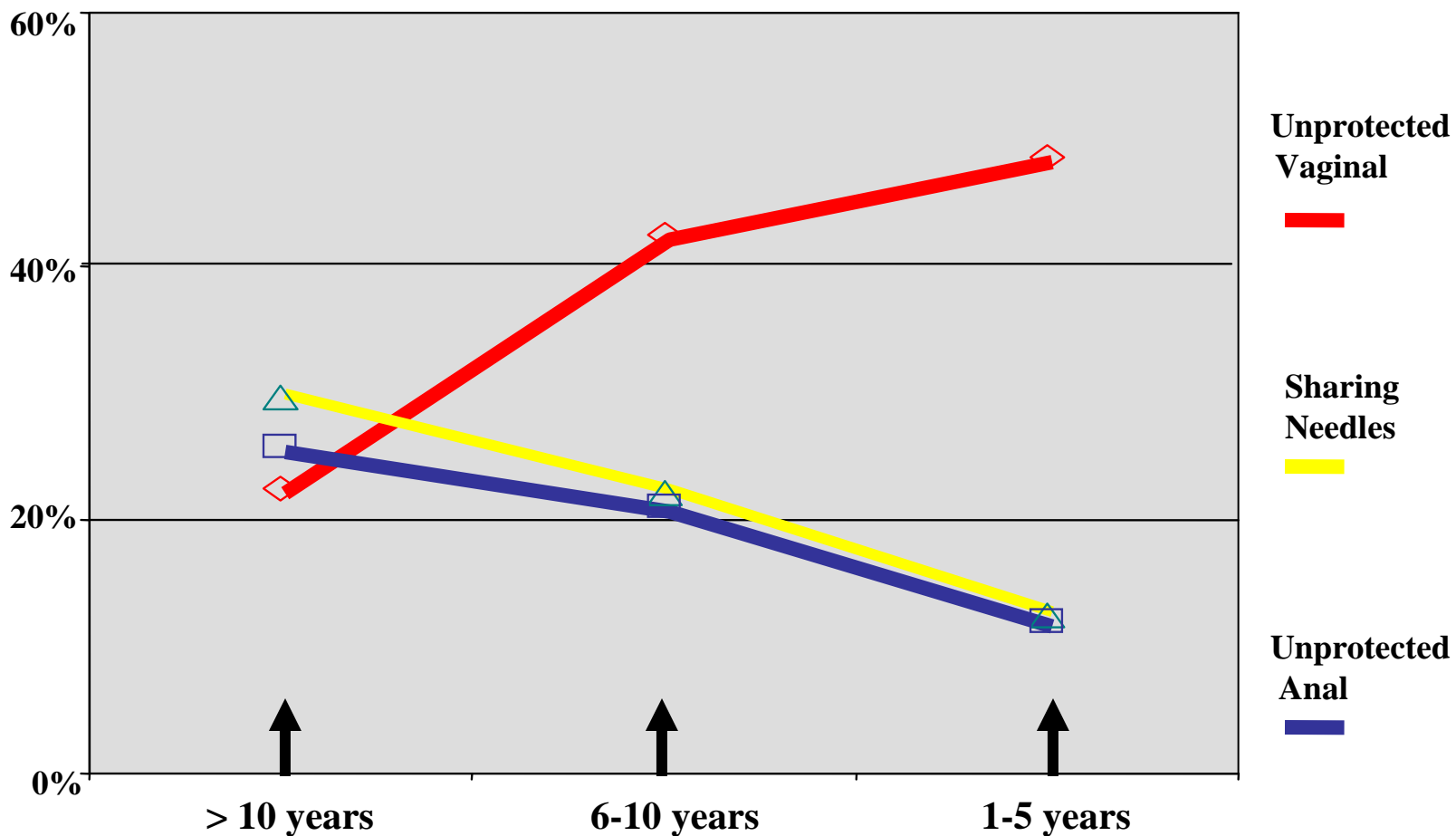
# ROAH Demographics

<b>Sexual Orientation</b>	<b>%</b>
■ Heterosexual	69.4
■ Bisexual	8.1
■ Gay / Lesbian	21.5

<b>History of Incarceration</b>	
■ Yes	45.5

# Transmission Mode in ROAH: The Changing HIV Population



# ROAH HIV Care

<u>Treatment facility</u>	<u>%</u>
■ Private physician	21.9
■ Public clinic / hospital	58.7
■ VA Hospital	4.9
■ ASO / day program	17.0

<u>Currently Taking ARVs</u>	
■ Black	87.3
■ Latino	84.8
■ White	85.3
■ Male	86.0
■ Female	83.0

# ROAH HIV Measures

	%
■ Tested prior to diagnosis	26.6
■ Received AIDS diagnosis	51.3
■ Currently taking HAART	85.3
■ Using CAM therapies	28.8

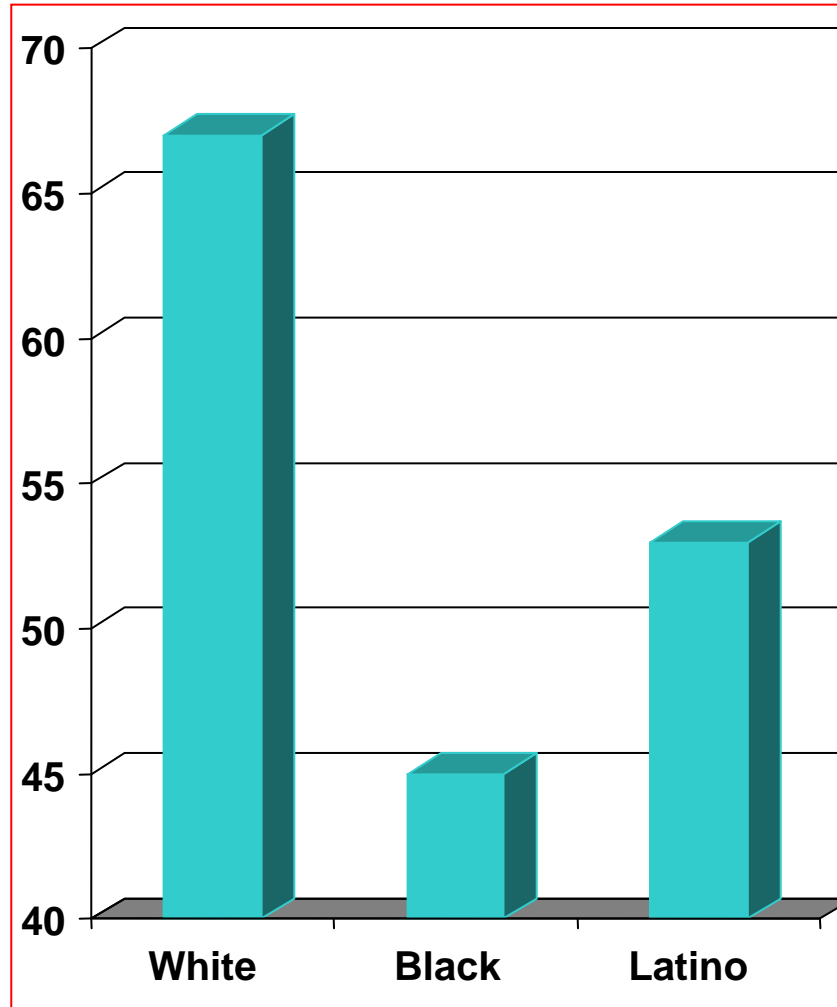
	X
■ Years since diagnosis	12.6
■ Months since last labs	3.7
■ Mean CD-4 count	468.2

# ROAH HIV Measures

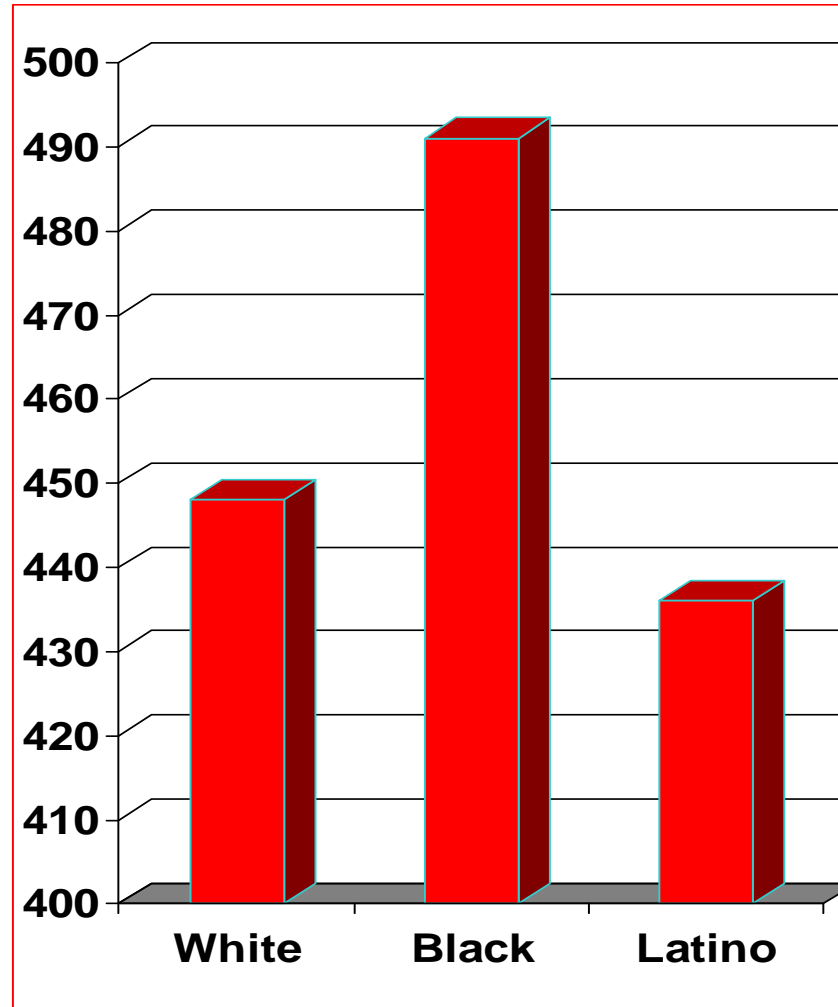
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	<i>X</i>
■ Years since diagnosis	
• Male	13.1
• Female	11.4
• White	14.9
• Black	11.8
• Latino	12.9

# % with AIDS Diagnosis



# ROAH CD4 Counts Reported



# ROAH: Disclosure Stigma

We asked

Do you discuss your HIV status with the following groups of people?

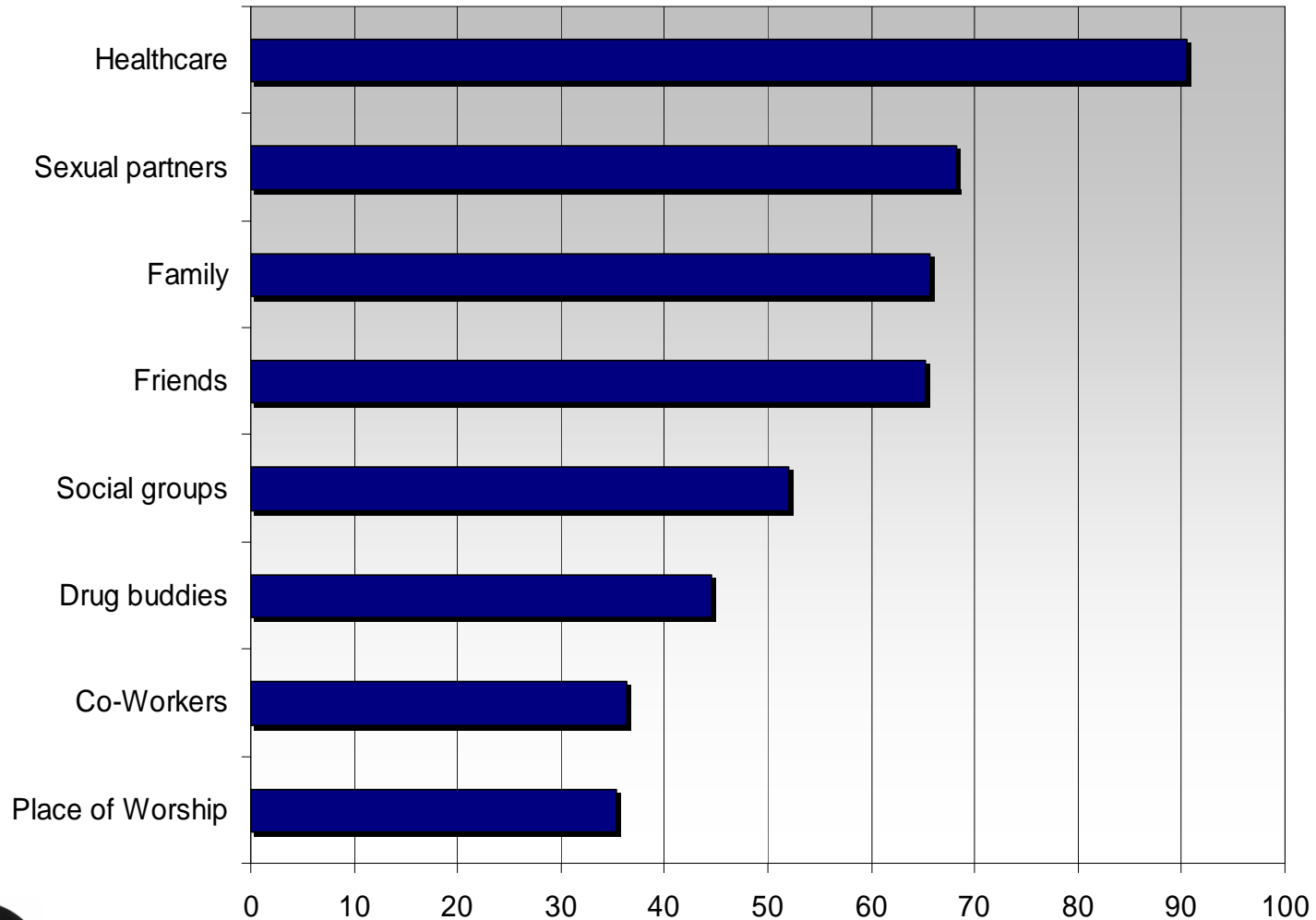
If so, are you open and honest with

- All / Most
- A few
- None

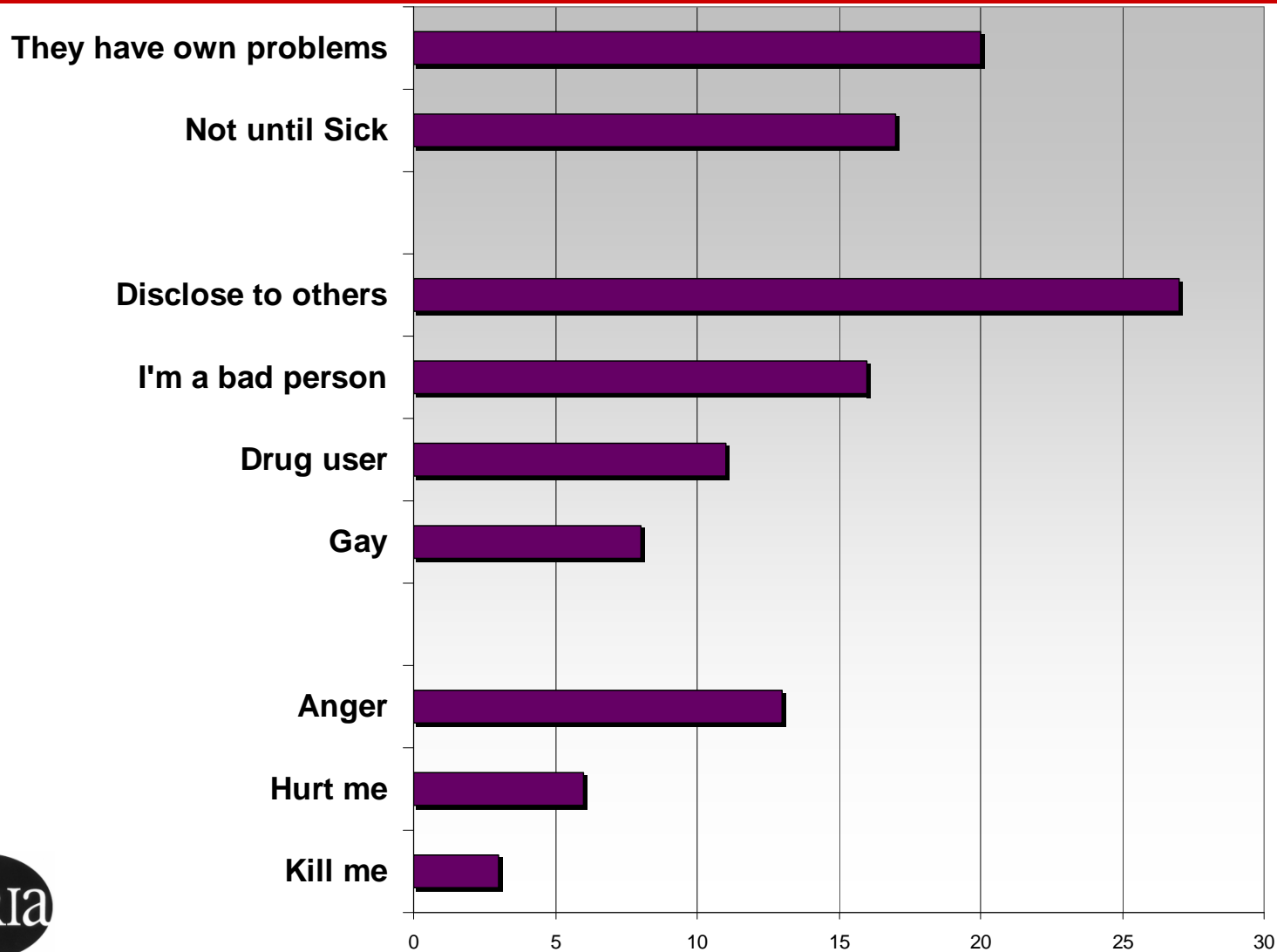
of the people in this group.



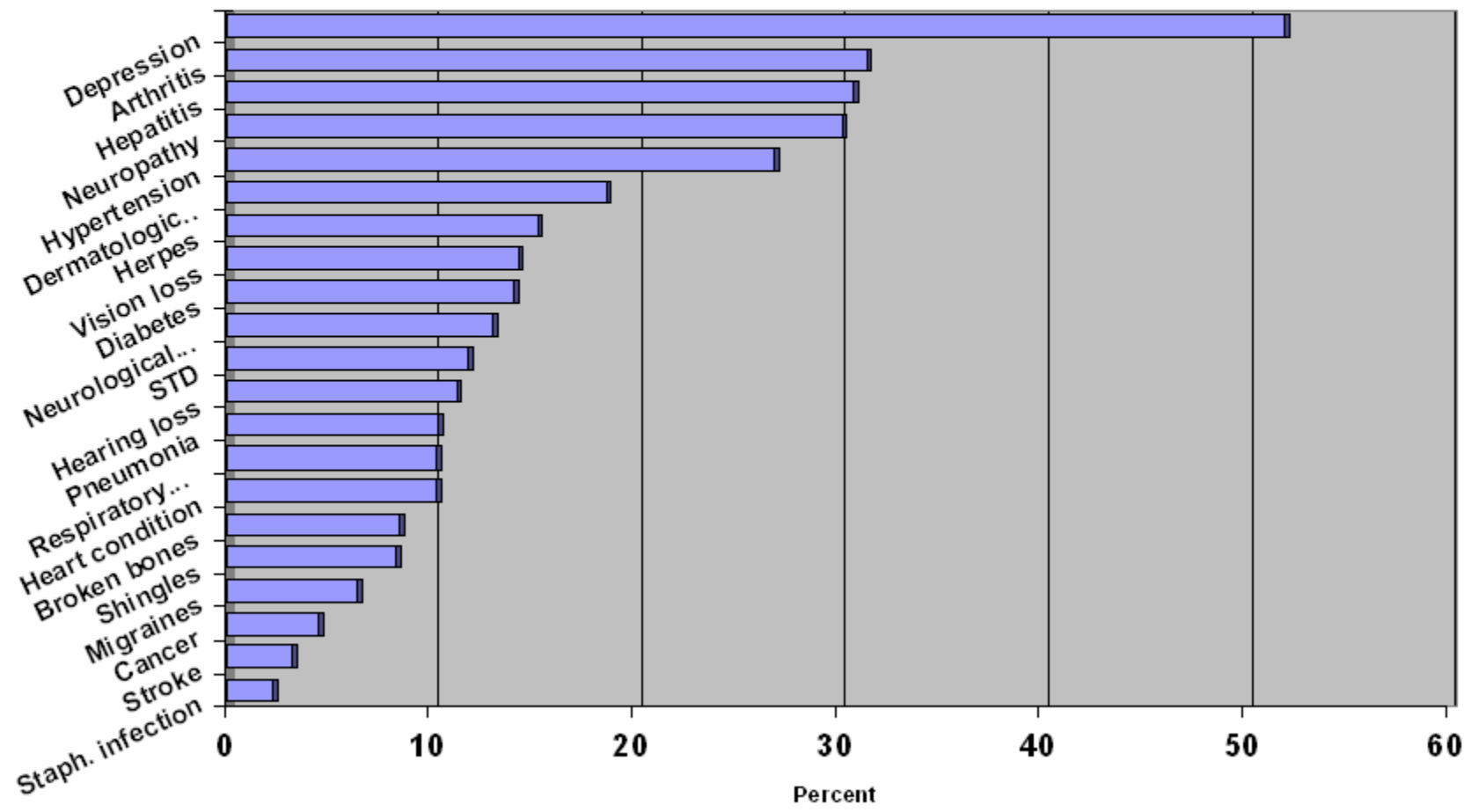
# ROAH: Disclosure of HIV Status



# ROAH: Reasons for Nondisclosure



# Comorbid Health Problems



# ROAH: Tobacco Use

**Current %**

*57*

**History %**

*84*

# ROAH: Depression

## **Life Satisfaction**

Very satisfied	23 %
Somewhat satisfied	55 %
Not too satisfied	19 %
Not at all satisfied	3 %

## **Self-rated Depression**

Yes	68 %
No	32 %

## **Treated Depression**

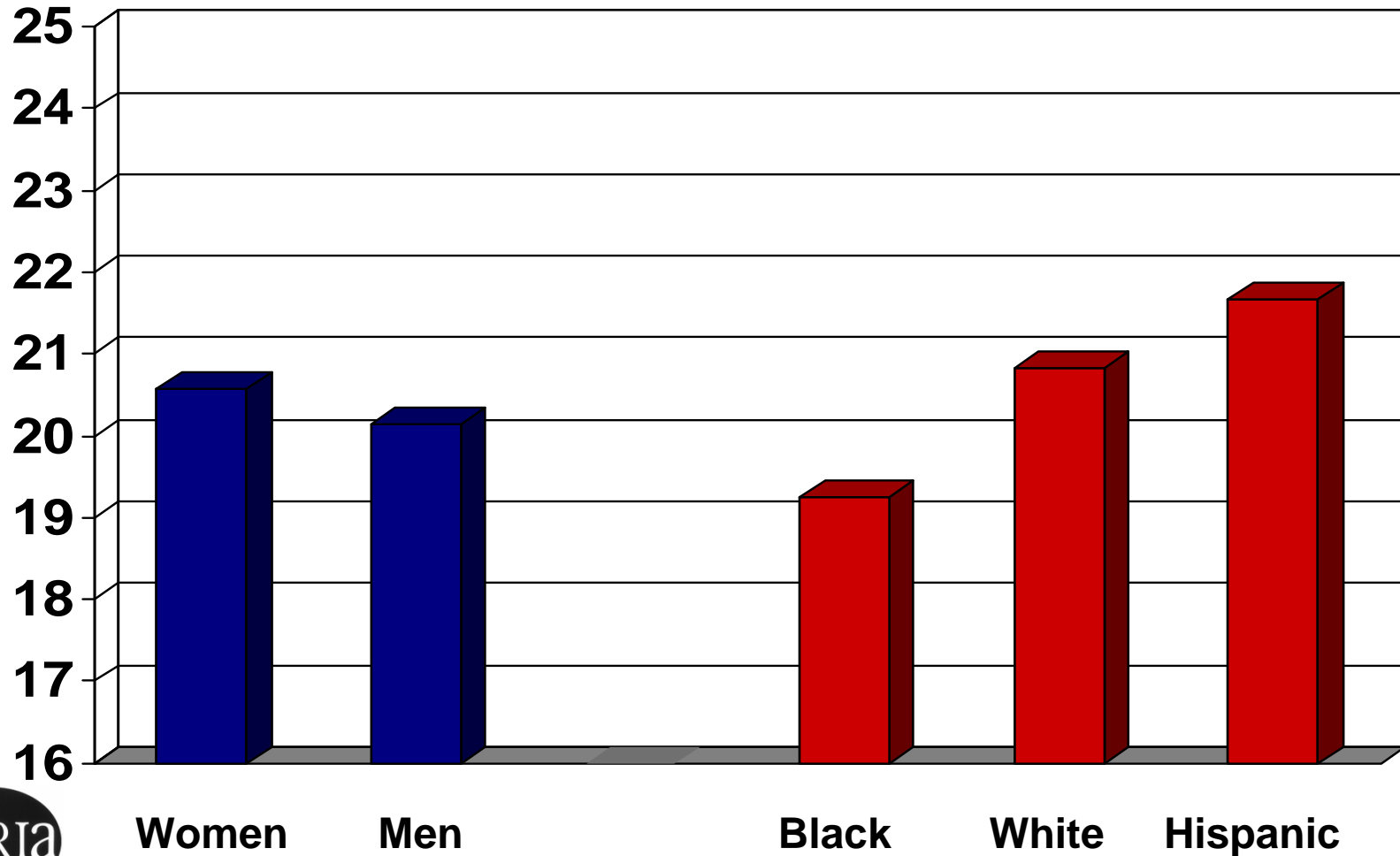
Yes	58 %
No	42 %

# ROAH: Symptoms of Depression

## Self-reported Depression (CES-D)

	%
■ No significant depressive symptoms	36
■ Moderate level of depressive symptoms	38
■ Severe level of depressive symptoms	26
■ When the 7 items that measure somatic symptoms were removed 45% scored above 16 indicating the impact of affect/mood.	

# CES-D Mean Scores: Depression Symptoms



Book Chapter from ROAH Data: In Press

# **Contributors to Depressive Symptoms in Older Women with HIV: Health and Psychosocial Stressors**

*Mark Brennan, Allison Applebaum, Marjorie Cantor, R. Andrew Shippy, and Stephen E. Karpiak*

AIDS Community Research Initiative of America (ACRIA)  
New York, NY, USA



- The sample consisted of 264 women, 50 to 76 years old (*M* age = 55 years). Approximately one-third had post-high school educations, 58% were Black and 34% Hispanic.
- To examine the impact of health-related and psychosocial stressors, the conceptual model employed for analysis was a modified Stress and Coping Model (Folkman and Lazarus, 1986).
- The multivariate model explained 47% of the variance in depressive symptoms.
- The number of comorbid conditions and the need for assistance as a result of HIV infection were positively related to greater depressive symptoms, as were both loneliness and stigma.
- Higher cognitive functioning and spirituality were significantly related to lower levels of depression.
- These findings support the need for interventions to address depression, health and psychosocial stressors among older women with HIV. In addition, programs to increase access to spiritual resources for older women with HIV could ameliorate depression in this population.

# ROAH Identifies 3 Factors

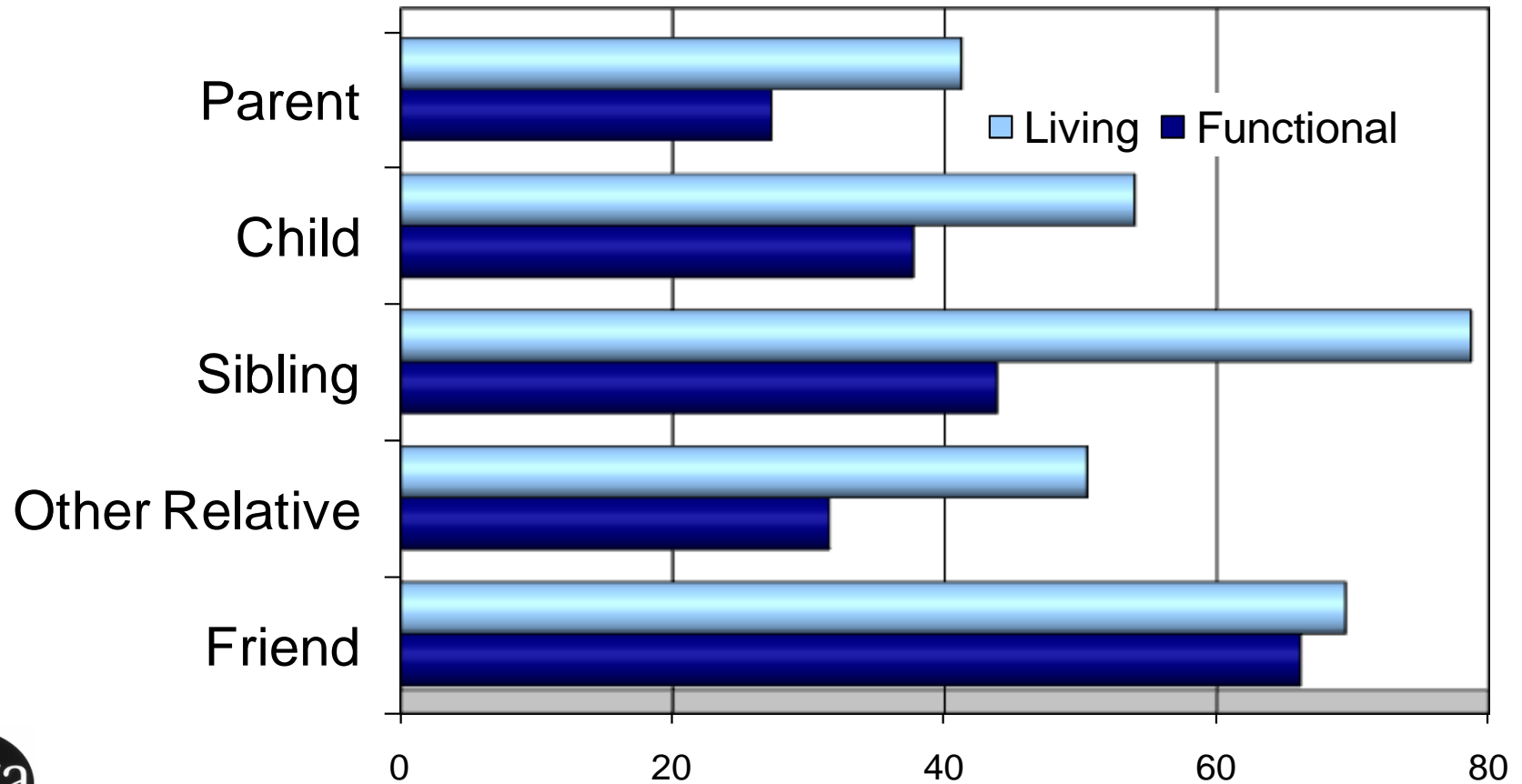
- Social Isolation
- Depression
- Loneliness

# ROAH: Caregivers and Social Networks

**CAREGIVERS**  
are derived from  
**SOCIAL NETWORKS**

**Social networks are a  
significant healthcare  
resource  
as people age**

# ROAH: Informal Network Composition



# ROAH: Substance Use

<u>Substance</u>	<u>Current %</u>	<u>History %</u>
■ Tobacco	57	84
■ Alcohol	38	81
■ Marijuana	23	71
■ Cocaine	15	63
■ Crack	16	47
■ Heroin	07	44
■ Crystal Meth	02	09

# ROAH: Substance Use

Recovery status of substance users	%
■ Ever enrolled in 12-step	62
■ Currently in recovery	54
■ No substance use in past 3 months	48
■ In recovery for more than 1 year	44

# ROAH Substance Use

- Blacks (58%) and Latinos (56%) are nearly twice as likely to be in recovery as Whites (32%)
- Men (41%) were significantly more likely to use substances than women (28%)
- People who use illicit substances report higher levels of stigma and they also report lower levels of spirituality

# ROAH Sexual Behaviors 3MOS

<u>Number of sexual partners</u>	<u>%</u>
■ No sexual partners	43.3
■ One sexual partner	43.4
■ More than one sexual partner	13.3

<u>Sexual activity in the last 3 months</u>	<u>%</u>
■ No sexual activity	49.8
■ Oral sex	41.4
■ Vaginal sex	30.1
■ Anal sex	19.5

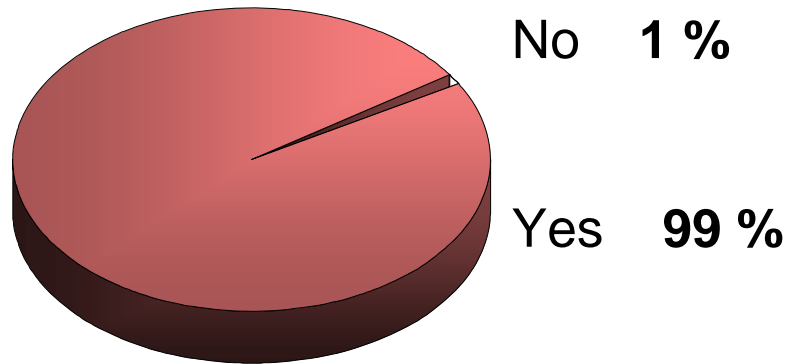


## ROAH: First Data Risk Behavior in Older Adults

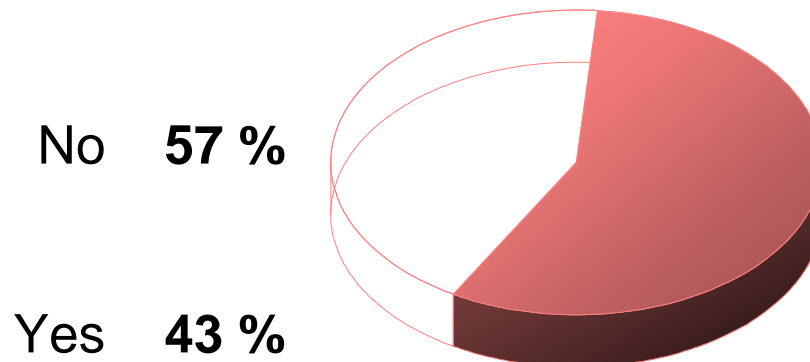
- Substance use impact - Significant
- Viagra and other ED Drugs Impact - None
- Of those who are sexually active  
16% engaged in high risk sexual behavior in the last 3 months

# Prevention for Positives

**Do you receive HIV prevention information?**



**Does prevention information target older adults?**



# Sexual Behaviors among HIV Positive Men over 50

David S. Bimbi, Ph.D<sup>1</sup> Julia Tomassilli, MA<sup>1,2</sup> Jeffrey T. Parsons, Ph.D.

<sup>1</sup> Stephen E. Karpiak, PhD <sup>4</sup>R. Andrew Shippy, MA.



- <sup>1</sup> Center for HIV/AIDS Educational Studies and Training (CHEST) @ Hunter College, City University of New York
- <sup>2</sup> Graduate Center of the City University of New York
- <sup>3</sup> Hunter College of the City University of New York
- <sup>4</sup> AIDS Community Research Initiative of America (ACRIA)

Presentation given at the CDC 2007 National HIV Prevention Conference  
Atlanta, GA, December 2007

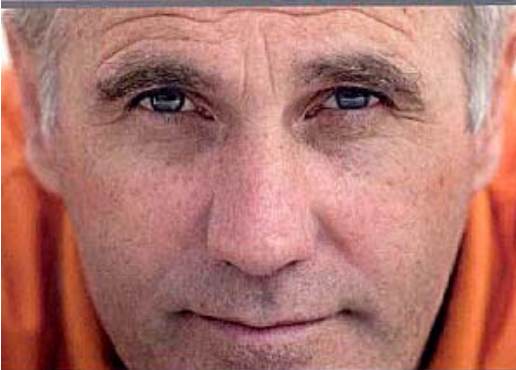


# New York City \$1 Million HIV Older Adults Initiative

- Target older adults service providers
- Technical assistance program
- Partnership with agencies serving older adults
- Create possibilities for networking between local HIV service providers and older adult serving agencies
- Change of knowledge, attitudes and beliefs
- Stigma of older adults (at risk and living with HIV)
- Tailored service integration
- Mainstreaming HIV/older adult services

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

## The Greying of HIV



### FREE TRAINING for Social Service and Healthcare Providers, and Peer Educators

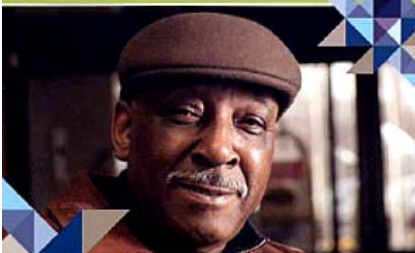
This growing population of older adults with HIV is often isolated and depressed, bearing the double stigma of HIV-phobia and ageism. As they age they may be cut off from the services they need. Other older adults rarely hear about HIV, and even more rarely about how they can protect themselves.

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

For info

Karol Mar  
Council of  
(212) 398

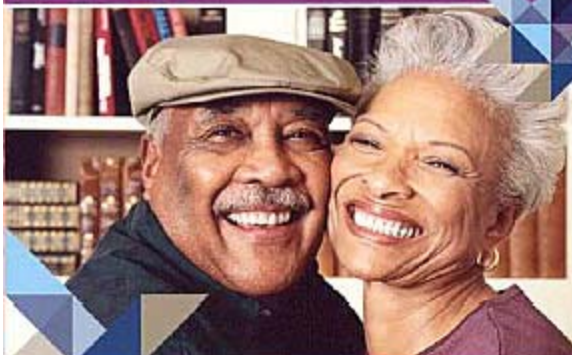
## Think you're too old for HIV?



### Think again.

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



Funded in whole by the New York City Department of Health and Mental Hygiene, the New York City Council Older Adults Initiative, the umbrella for the trainings being offered, is the result of a collaboration of the City Council Committee on Aging, Maria del Carmen Arroyo, Chair; and the City Council Committee on Health, Joel Rivera, Chair.

# Stop HIV/AIDS



## Some say HIV's only for young folks.



You've lived too long to believe that nonsense.

## Get tested for HIV.

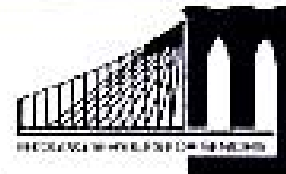
City Hygiene



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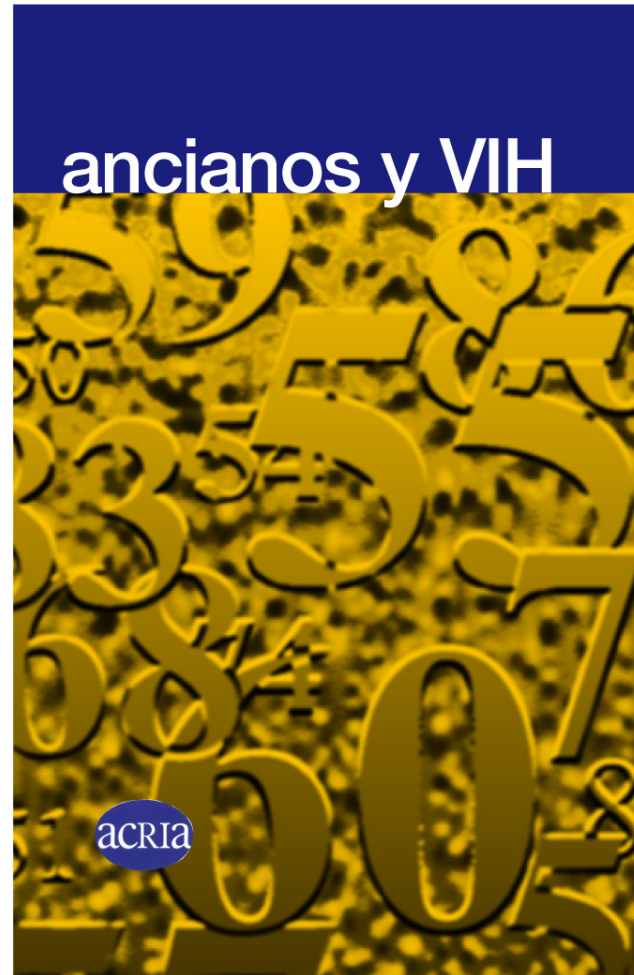


ACRIA  
AIDS COMMUNITY RESEARCH  
INITIATIVE OF AMERICA  
[www.acria.org](http://www.acria.org)



CSCS  
COUNCIL OF SENIOR CENTERS AND  
SERVICES OF NEW YORK CITY, INC.  
[www.cscs-ny.org](http://www.cscs-ny.org)

# ACRIA's HIV Older Adults Booklet



# ACRIA

**AIDS Community Research Initiative of America**

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## ROAH

Research on Older Adults with HIV

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