



UNIVERSITY OF MIAMI

SCHOOL of NURSING  
& HEALTH STUDIES



# Research Participation Decision Factors and Data Collection Modality Preferences among Minority Adults Living with HIV

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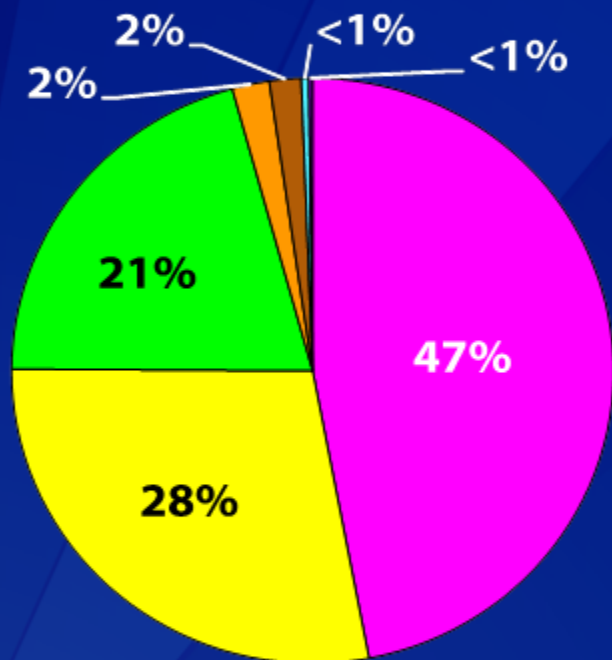
## STTI 25th International Nursing Research Congress

This research was funded by the Miami Center for AIDS Research (CFAR; P30AI073961). Support for this research was also received from the Center of Excellence for Health Disparities Research: El Centro, National Institute of Minority Health and Health Disparities grant P60MD002266. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

# Diagnoses of HIV Infection and Population by Race/Ethnicity, 2011—United States

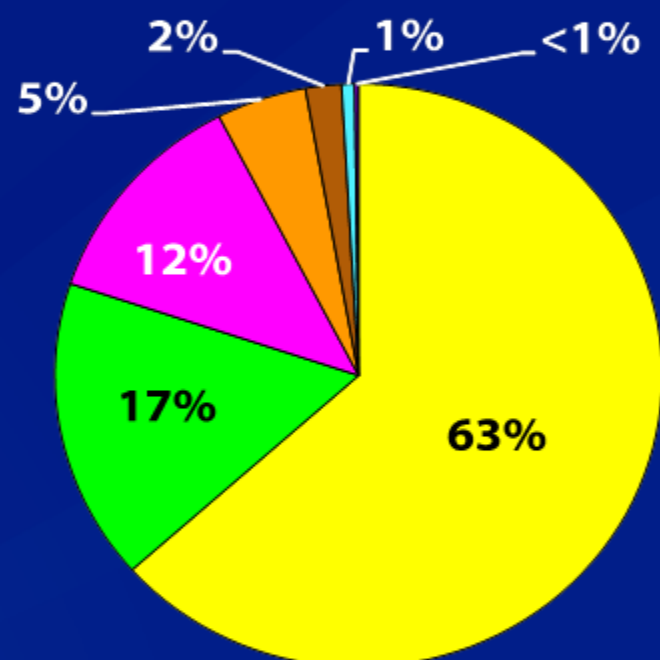
## Diagnoses of HIV infection

N = 49,273



## Population, United States

N = 311,591,917



American Indian/Alaska Native

Asian

Black/African American

Multiple races

Hispanic/Latino<sup>a</sup>

Native Hawaiian/other Pacific Islander

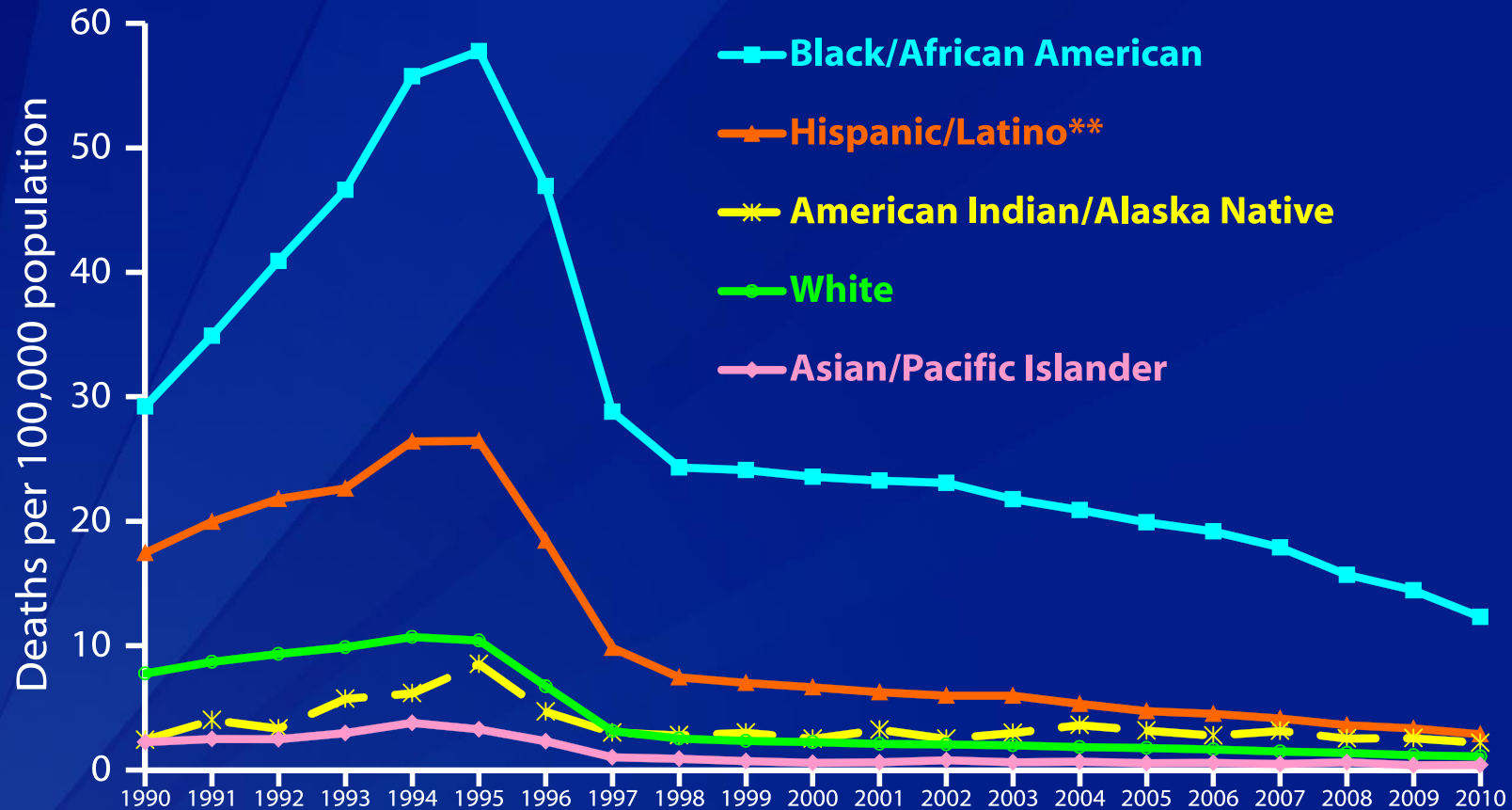
White

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

<sup>a</sup> Hispanics/Latinos can be of any race.



# Trends in Age-Adjusted\* Annual Rates of Death due to HIV Infection by Race/Ethnicity, United States, 1990–2010



Note: For comparison with data for 1999 and later years, data for 1990–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.

\*Standard: age distribution of 2000 US population

\*\* Hispanics/Latinos can be of any race.



# Underrepresentation of Minorities in HIV/AIDS Research

Giffords et al., 2002. Nationally representative data from the HIV Cost and Services Utilization Study (n=2864; 1996-1998)

	Proportion of total receiving HIV Care	Proportion of total AIDS cases	Proportion of total in HIV Med Trials
White, NH	49%	44%	62%
Black	33%	37%	23%
Hispanic	15%	18%	11%

Sullivan et al, 2007.  
Population-based sample of HIV+ individuals in 15 states from Supplement to HIV and AIDS Surveillance (SHAS) Project (n=6892; 2000-2004)

**Percent of HIV+ individuals who had ever participated in HIV clinical research**

	Men	Women
White, NH	23	16
Black	15	15
Hispanic	14	17

# Consequences of Underrepresentation

- Limits to external validity of research
- Unequal opportunity for benefits
- In 1994, the NIH established guidelines mandating inclusion of women and minorities in epidemiologic and clinical studies



# Reasons for Non-Participation in HIV Research

- Believing they do not qualify
- Distance from research environment/ transportation limitations
- Not wanting to be a “guinea pig”
- Mistrust of researchers (perception that the informed consent process is primarily to protect physicians and hospitals)
- Feeling too sick to participate
- Language and literacy barriers (difficulty in understanding consent form terminology)
- No guarantee of being in the treatment arm
- Too much of a hassle
- Not in care

**#1 Reason: Lack of knowledge/not being invited to participate**

- **Provider bias in referring racial/ethnic minorities to studies**
- **Minority Individuals DO want to participate – however, barriers and preferences need to be addressed**

# Community/Social Endorsement Approaches to Increase Minority Research Enrollment

- CBPR
- Buy-in/endorsement from community leaders
- Snowball sampling
- Minority research team members



# Cost/Benefits of Research Participation

## Costs

- Time/effort
- Burden of complex or difficult to understand procedures
- Risks
  - Side effects of treatment
  - Loss of dignity
  - Loss of privacy

## Benefits

- Receiving services or treatment
- Monetary compensation
- Making a contribution to society





# Data Collection Modalities

- Computer-assisted data collection technologies (tablets, CASI, A-CASI)
  - +Maximizes privacy
  - +Reduces data entry effort and error
  - +A-CASI addresses literacy limitations
  - Intimidating/impersonal
- Paper questionnaires
  - +Convenient and low cost
  - Risk of disengagement
- Face to face interview
  - + Personal
  - Expensive
  - Risk of social acceptability bias



# Aims of the Study

- Among adults living with HIV,
  - Describe the importance of cost/benefit and community/social endorsement factors when deciding whether to participate in a research study
  - Describe their comfort with three data collection modalities: face-to-face interview, paper survey and private computer screen
  - Examine whether the decision factors and comfort with the data collection modalities are related to participant characteristics (ethnicity, gender, age, education, or first-time study participation)

# Methods

- Secondary analysis from a cross-sectional study
- Participants were 453 English-speaking adults living with HIV and attending two large HIV primary care clinics in Miami-Dade County Florida
- Study staff approached every third person that checked in for HIV health care services
- \$10 compensation
- IRB approved

# Participant Characteristics

- 57% Male
- 60% African American
- 35% Hispanic
- Mean age = 45.97 years ( $SD = 9.17$ )
- 75% unemployed
- 64% with high school education
  - Hispanics and Whites were more likely to have high school education than African Americans
- Time since HIV diagnosis
  - 57% more than 10 years
  - 21% 5-10 years
  - 17% 1-5 years before
  - 5% less 1 year
- 90% taking HIV medications
- 70% with previous research experience

# Measure: Decision Factors

How important are the following when you are deciding whether or not to participate in a research study: Not important (1), important (2) or absolutely important (3)?

a. being sure about the confidentiality of your information\*

b. understanding what the study is all about\*

c. that the study is not much of a hassle\*

d. receiving a benefit from the study (for example, services, information, treatment)\*

e. society benefiting from the study\*

f. being treated with respect\*

g. someone you know participating in the study\*\*

h. someone similar to you working in the study\*\*

i. a leader in your community (for example, a pastor or a teacher) approving of the study\*\*

j. your health provider approving of the study\*\*

\*Factor 1: Cost/Benefits,  $\alpha = .88$

\*\* Factor 2: Community/Social Endorsement,  $\alpha = .93$ .

# Measure: Data Collection Modalities

If you were being asked very personal questions in a research study (for example about HIV, sex, or drug use) how comfortable would you be answering,

	Very uncomfortable	A little uncomfortable	Comfortable
a. face to face with an interviewer	1	2	3
b. on a paper questionnaire that you fill out yourself	1	2	3
c. in private, on a computer screen while hearing the questions read to you on earphones	1	2	3

# Results: Importance of Research Participation Decision Factors

- Cost/benefit,  $M = 2.50$ ,  $SD = 0.46$ , rated as more important than community/social endorsement,  $M = 2.11$ ,  $SD = 0.70$ .
- Cost/benefit items rated as “absolutely important” by the majority of participants,
  - confidentiality of information (66%)
  - being treated with respect (63%)
  - understanding the study (57%)
  - societal benefit (53%)
- Community/social endorsement item most often rated as absolutely important:
  - that a health provider approved of the study (44%)

# Results: Comfort with Data Collection Modalities

Comfort with Format	Very uncomfortable		A little uncomfortable		Comfortable	
Face to face	11	2%	19	4%	423	93%
Paper	18	4%	73	16%	361	80%
Computer	73	16%	60	13%	319	70%



# Results: Importance of Decision Factors by Participant Characteristics

- Logistic regressions
- No differences by ethnicity, age or education
- Participants in their first study,
  - less likely to say cost/benefits were important,  $B = -0.47$ ,  $SE = 0.21$ ,  $p = .025$ ,  $OR = 0.63$ .
  - less likely to say community/social endorsement was important,  $B = -0.60$ ,  $SE = 0.23$ ,  $p = .008$ ,  $OR = 0.5$ .

# Results: Comfort with Data Collection Modalities by Participant Characteristics

- Ethnicity unrelated to preference
- Older age associated with greater preference for face-to-face interviews,  $B = 0.78$ ,  $SE = 0.21$ ,  $p < .001$ ,  $OR = 2.18$ ,
  - every ten additional years of age related to more than twice the odds for preferring a face-to-face interview
- High school grads vs non-grads,
  - more likely to prefer paper survey,  $B = 0.65$ ,  $SE = 0.25$ ,  $p = .008$ ,  $OR = 1.91$
  - more likely to prefer a private computer screen,  $B = 0.44$ ,  $SE = 0.22$ ,  $p = .044$ ,  $OR = 1.55$
- Participants in their first study less likely to prefer face-to-face interviews,  $B = -0.82$ ,  $SE = 0.40$ ,  $p = .041$ ,  $OR = 0.44$  than those with previous experience

# Take Home Points

- No ethnicity or gender differences
- Cost/benefits
  - Confidentiality and R-E-S-P-E-C-T are key
  - Altruism as a motivational factor
- Social/community endorsement
  - Health care providers carry a lot of clout
  - Are they informing their minority patients? – This is the #1 barrier
- Data collection modalities
  - More people uncomfortable with computer, especially older and less educated
  - Need to balance respect and need for privacy: provide extra assistance and personal touch if using A-CASI



# Limitations

- Hispanics limited to English-speakers
- Limited to 2 sites in 1 city
- Instruments not previously validated
- Research refusers not included

Thank  for your attention

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