

The Role of Intersectional Stigma in HIV Research:  
Identifying Risks and Benefits of Research  
Participation among HIV-Positive African American  
Women

**Nicole M. Overstreet, PhD**

**Clark University**

**Worcester, MA**



**CLARK**  
UNIVERSITY

# African American Women and HIV

- Decrease in incidence of HIV infections among African American women
- However, among women, racial/ethnic disparities in HIV remain. New HIV infections among African American women are:
  - 5 times that of Hispanic women
  - 20 times that of White women
- HIV research is vital to understanding and reducing barriers to HIV treatment and ameliorating health disparities

# HIV Research and Marginalized Populations

- Recruitment may be stymied by concerns about participation harms
- Concerns about participation harms rooted in historical medical maltreatment often at the intersection of race, gender, and class (Washington, 2006)
  - E.g., Henrietta Lacks
- Stigma may be an additional concern in HIV research
  - Devaluation associated with status loss and discrimination (Goffman, 1963; Link & Phelan, 2001)
  - Research process may make power dynamics salient and increase concern that participation will be linked to status loss

# Ethical Considerations in Scientific Research

- Research suggests that medical mistrust and stigma may shape ethical concerns in the research process among marginalized groups in the following ways (Drotar, 2008; Sieber, 2008):
  - Fears about breach in confidentiality
  - Concerns about privacy
  - Participant discomfort in answering research questions
  - Increased psychological distress
  - Consent
- *Mitigating social harms is a primary goal in research ethics, yet our understanding of ethical concerns is seemingly detached from the intersecting identities and interlocking oppressions that marginalize groups experience.*

# Research Goals

- Intersectionality as a framework to understand how African American women's intersecting identities (e.g., gender, class, HIV+ status) shape perspectives on benefits and concerns (e.g., confidentiality, participant distress) about participating in HIV research
- Discuss how perspectives can enhance responsible conduct of HIV research with African American women

# Method

- 97 African American women living with HIV
  - $M_{\text{age}} = 47.96$ ,  $SD = 9.48$  (Range 24-65)
- Recruited at HIV care clinic in Baltimore, MD
- Procedure:
  - Participants first completed the Women's Health Study (parent study), which examined HIV, intimate partner violence, and mental health
  - After Women's Health Study, participants completed current study: a retrospective online survey on iPad asking about their experience participating in Women's Health Study
  - Open-ended questions asking about perceived benefits and risks of participating in Women's Health Study
  - Quantitative questions assessing stigma associated with intersecting identities, benefits/risks of research participation
  - **Will focus on open-ended responses**
- Remuneration: \$50 gift card

# Method

- Three open-ended questions
  - Question 1: What was the greatest benefit of participating in the Women's Health Study?
  - Question 2: What was your greatest concern about answering questions in the Women's Health Study?
  - Question 3: What do you think was the purpose of the Women's Health Study?

# Method

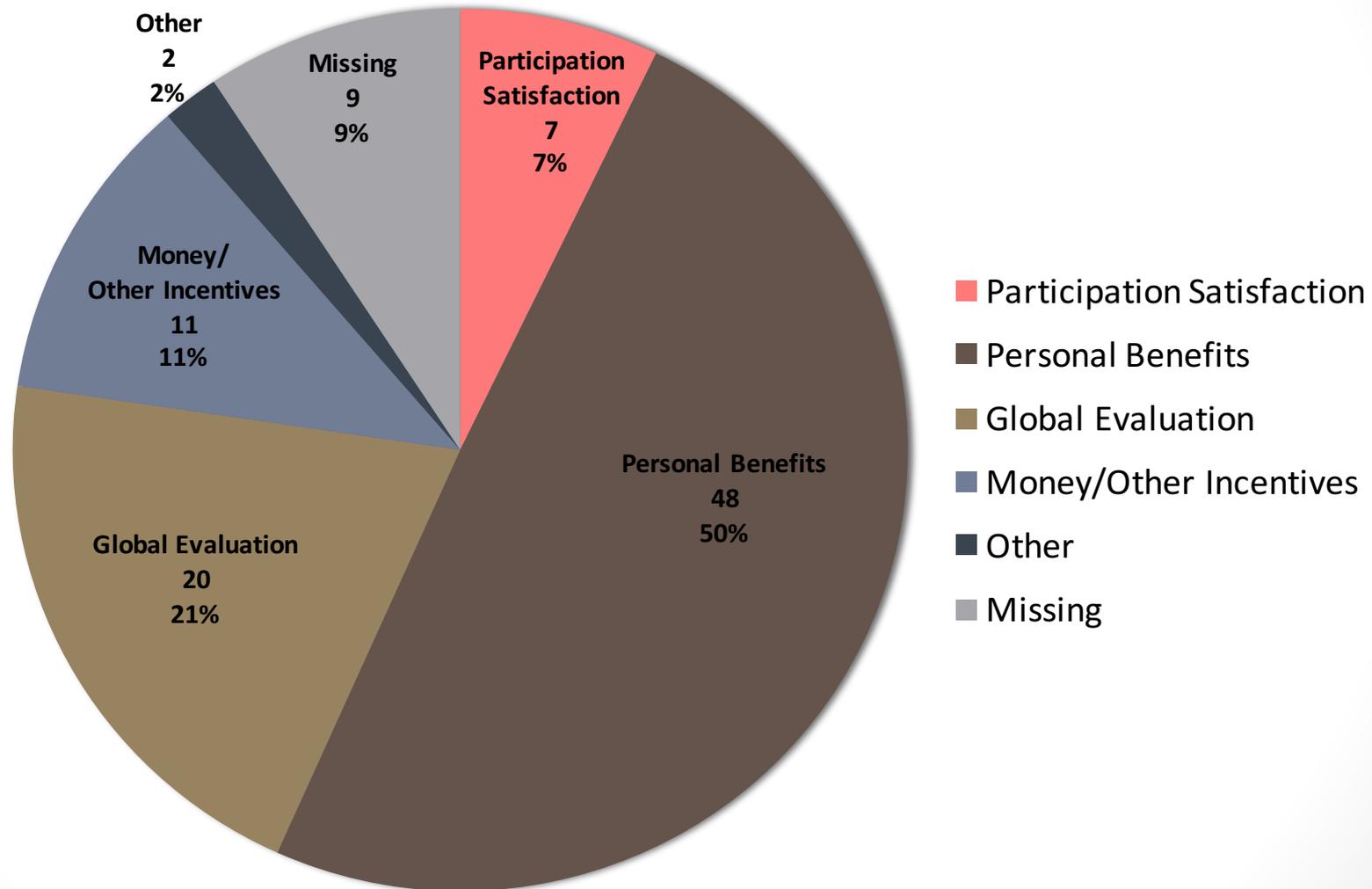
- Open-ended questions
  - **Question 1**: What was the greatest benefit of participating in the Women's Health Study?
  - **Question 2**: What was your greatest concern about answering questions in the Women's Health Study?
- Codes (Newman, 2001; Drotar, 2008; Sieber, 2008)

Q1 (K = .75)	Q2 (K = .88)
Participation Satisfaction	Emotional Reactions
Personal Benefits	Perceived Drawbacks
Global Evaluation	Confidentiality
Money/Other Incentives	Social Desirability
Other	No Concerns
	Answering Sensitive Questions
	Other

Total # of  
statements  
coded: 291

# RESULTS

# What was the greatest benefit of participating in the Women's Health Study?



# Greatest Benefit

## *Personal Benefits: 50%*

### Opportunity for self-reflection

- “Give me some time to think about my life and the questions that was ask”
- “Getting to see where I am today as far as the past to the present”
- “Seeing how blessed I am based on the questions asked”

### Benefits specifically linked to health/HIV

- “They help with my meds”
- “To have a better and positive understanding of how important it is caring for myself”
- “Getting better with myself and my health”
- “Learning more about the disease”

### Identifying unhealthy relationships

- “I realized I was in an abusive relationship”
- “Helped me understand the difference between violent parts of a relationship that might require some help”
- “Getting abuse advice and assistance”

### Source of social support

- “Being able to know you have great people who support you and are willing to help you”
- “The info I got”
- “To express feelings”
- “Education that you get from it and the person that’s having the study is caring about you”

# Greatest Benefit

## *Global Evaluation: 21%*

Research was for a good cause/useful to others

- “To help others”
- “The possibility that it may help another”
- “That I will be able to help someone”
- “The fact that I’m helping with a cause”

Respect and dignity by the research team

- “The concern they show”
- “The ease of taking the study questions. Was grateful to see questions related to partner violence both physical and emotional”

Being able to help others living with HIV

- “To get positive feedback that can help women with HIV”
- “Provide input to help HIV+ people have better quality of life”

# Greatest Benefit

## *Incentives, Participation Satisfaction, Other*

Incentives

11%

- “Walmart gift card helps with monthly expenses”
- “Transportation”
- “That you can talk about what you have been through in your life and there is someone out there in the world that cares what happens to you and it’s not bad that you can get a gift card too”

Participation  
Satisfaction

7%

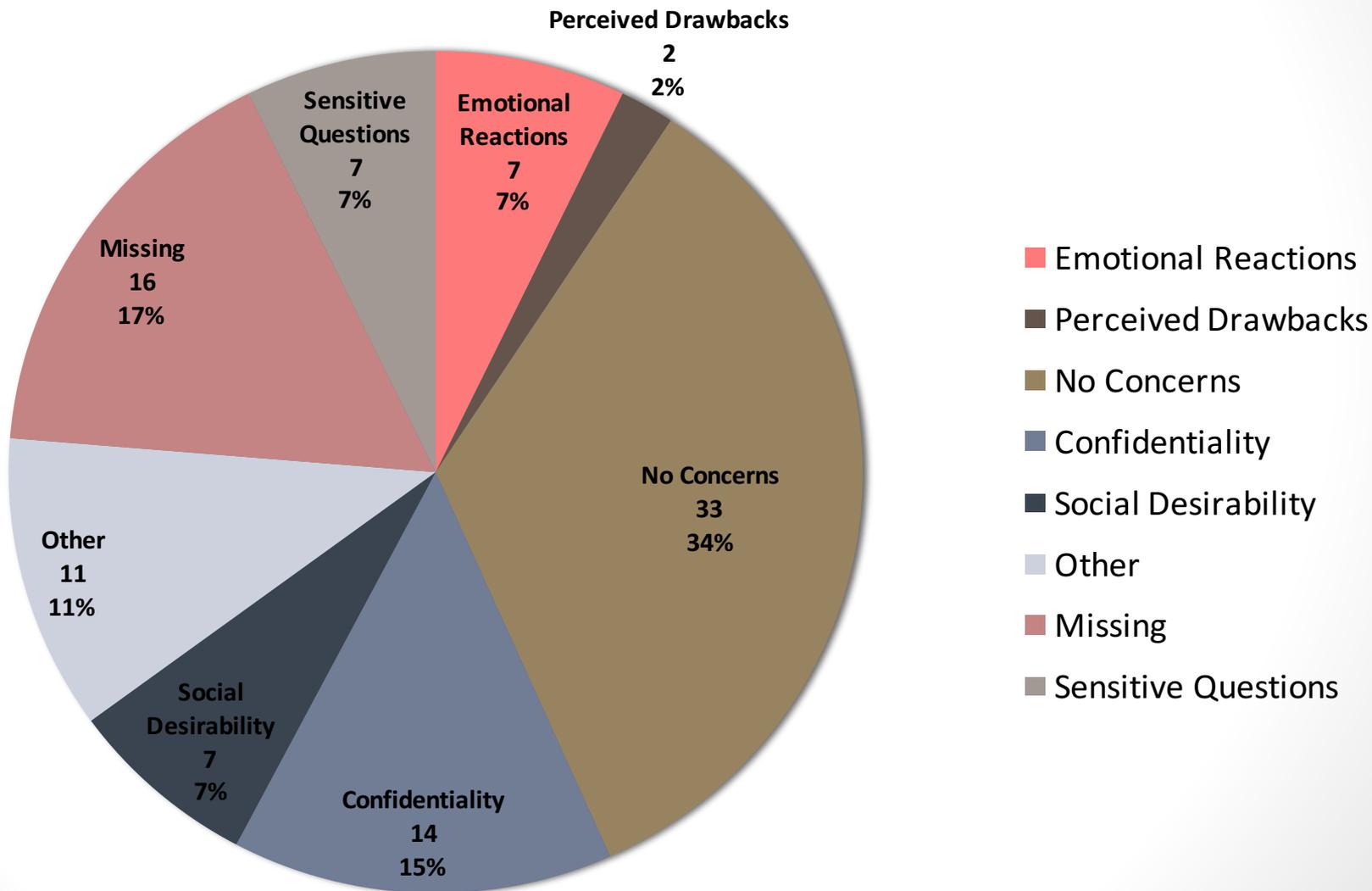
- “Enjoying answering questions”
- “It was good, I enjoyed it”
- “I just like being in studies”

Other

2%

- “Letting off”

# What was your greatest concern about answering questions in the Women's Health Study?



# Greatest Concern

## *Confidentiality and Other Concerns*

### Confidentiality

15%

- “Would my input stay confidential concerning the government programs that currently assist me with rent and income”
- “Other people getting my personal records”
- “If my friend would ask me what was it about”
- “That you will tell and I don’t want you to do that”
- “My greatest concern was my information being shared but I was assured that it was safe”

### Other

11%

- “Knowing more”
- “Knowing the truth”
- “Honesty”
- “Good”

# Greatest Concern

## *Emotional Reactions, Sensitive Questions, Desirability*

### Emotional Reactions

7%

- “Being truthful”
- “ Being real with self”
- “Just being scared in general to bring it up”

### Sensitive Questions

7%

- “The abusive part”
- “About the abuse”
- “That my mate was violent”
- “When you were asked if you were having anal sex”

### Social Desirability

7%

- “Whether I answered wrong or right”
- “I was worried about what people would think of me”
- “Answering them truthfully”

# Discussion

- Overall, African American women expressed positive reactions towards participation in HIV research
- Intersection of HIV and intimate partner violence reality for many women in the sample
- Intersectional identities influenced research concerns (e.g., confidentiality, reactions to sensitive questions)
- Important for research process:
  - Barriers to recruitment
  - Validity of Study Responses
  - Addressing Concerns in Informed Consent and Debriefing Process

# Future Directions: Intersectionality and Research Ethics

- Draws our attention to ***interlocking*** systems of oppression
  - Ethical violations often occur at critical intersections (e.g., race, gender, class)
  - Important to acknowledge history and consider how it may shape ethical concerns
- Pushes us towards ***eradicating*** inequality and social inequities

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# Thank you

[Noverstreet@clarku.edu](mailto:Noverstreet@clarku.edu)