

Negotiating and Managing Disclosure: Privacy Protection and Self-disclosure Patterns of HIV Positive Status among Urban HIV-infected African American Men

AARON G. BUSEH, PHD, MPH
ASSOCIATE PROFESSOR

PATRICIA E. STEVENS, PHD, RN, FAAN
PROFESSOR

SHERYL T. KELBER, MS, BIostatistician

CHANG GI PARK, PHD, RESEARCH SPECIALIST

NANCY NYUGEN
UNDERGRADUATE NURSING STUDENT

PRESENTATION AT: THE AMERICAN PUBLIC HEALTH ASSOCIATION
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Introduction: Disclosure Among People Living with HIV/AIDS

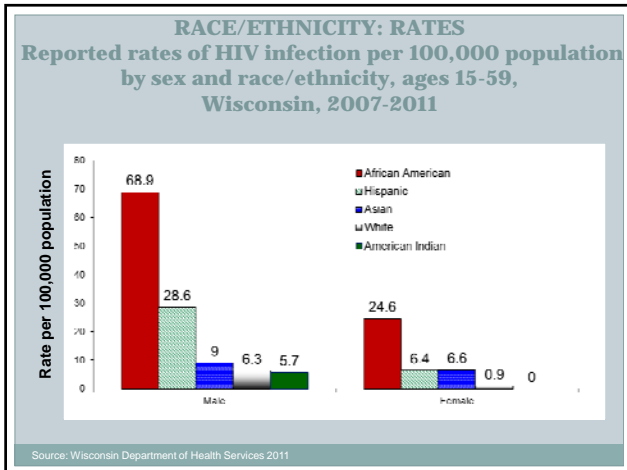
- Newly diagnosed individuals are faced with an important decision regarding whom they should share this information.^{1,2}
- Disclosure of one's HIV seropositivity is often perceived as a double-edged sword.
- Disclosure may open up the opportunity for receiving social support; however, it may lead to stigmatization, discrimination, disruption of interpersonal relationships.³
- Conversely, concealing one's HIV status from others may be stressful in itself and may interfere with obtaining and adhering to potentially critical medical treatment.²
- There is limited understanding and information on the process of disclosure among urban Black males.

Learning Objectives

- Identify interpersonal factors associated with disclosure processes among urban African American males living with HIV/AIDS;
- Discuss patterns of disclosure; and
- Describe reasons for disclosing or not disclosing HIV positive status.

Introduction: HIV/AIDS; A Health Crisis for African American Men

- African Americans make up about 14 percent of the U.S. population, but accounted for 44% of all new HIV cases in 2009.⁴
- AIDS is one of the leading cause of death for African American men in the U.S. aged 25-44.⁴
- At some point in their life, 1 in 16 black/African American men will receive a diagnosis of HIV.⁵
- In 2009 the estimated rate of new HIV infection for black/African American men was more than 6 times as high as white men, nearly two and a half times that of Hispanic/Latino men.⁵
- Complex web of factors including stigma and discrimination presents challenges of preventing HIV infection among African American men.



Negative and Positive Consequences of Disclosing an HIV Diagnosis

Negative Consequences	Positive Consequences
• Social isolation and ostracism	• Relationship may become closer
• Physical violence	• Opportunity for educating others
• Victim blaming and shame	• Practice lower risk partners may get tested
• Relationship ends (also divorce)	• Able to talk about stresses
• Cannot see children, nieces, nephews	• Reminded to take medicines, eat well
• Lost housing, evicted	• Others prepared meals, helped with chores
• Employment discrimination	• Financial assistance (rent, meals, medication)
• Difficulties in obtaining insurance	• Assistance provided with child care
• People may not speak to you	• Met others with HIV/AIDS
• Disowned (by parents/family/friends)	• Received help with filling out forms, using internet
• People will not eat food prepared	• Joined support groups, visited AIDS service organizations

Source: Greene et al., (2003). Privacy and disclosure of HIV in interpersonal relationships: A source book for researchers and practitioners. Lawrence Erlbaum Associates, Publishers. Mahwah, New Jersey.

Purpose

Using a narrative inquiry approach, the objectives of this study were:

- **Explore factors that necessitates HIV disclosure among a sample of urban HIV-infected African American men;**
- **Describe mode or strategies used in disclosing their HIV positive status to others; and**
- **Describe the experience of stigma and how stigmatizing experiences impacted decisions to disclose or not disclose sero-positive status.**

Methods and Procedures

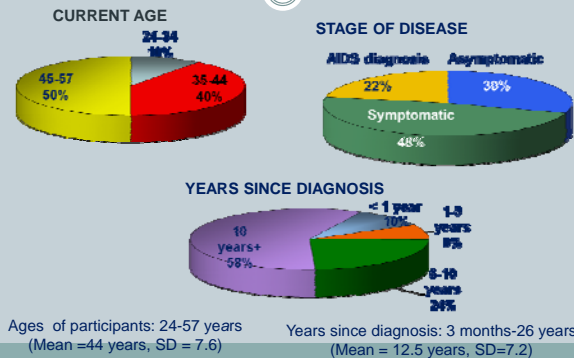
- **Qualitative cross-sectional narrative inquiry design**
- **Sample: Purposive sample of (n =50) African American men self-reported as being HIV infected**
- **Setting of study: Metro Milwaukee, Wisconsin, USA**
- **Recruited from a local African American community-based organization that serves predominant Blacks**
- **Completion of an informed consent**
- **Completion of a brief socio-demographic form and in-depth interview lasting approximately 1hr 30mins**
- **Verbatim transcripts managed using QRS N-VIVO® 9.0 computer software**
- **Data analyzed using qualitative thematic narrative analysis approach**

Results

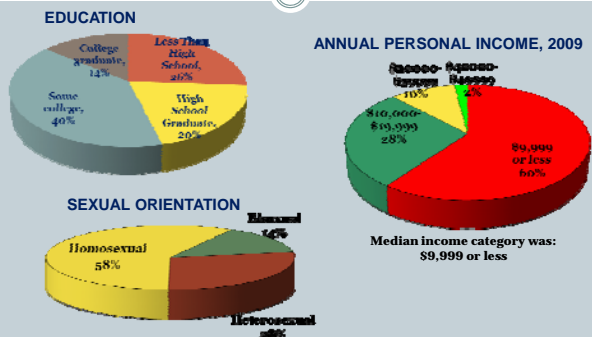
• Major themes emerging from analysis of the narratives are grouped and presented under the following categories/themes and followed by exemplars:

- ❖ Reasons for disclosure: Unburdening stress and wanting resources
- ❖ Reasons for Non-Disclosure: Calculating social stigma as risk factor influencing non-decision disclosure
- ❖ Mode and strategies used in disclosing HIV status to others

Description of the Participants: Age, Stage of Disease, Years Since Diagnosis, Education (N =50)



Description of the Participants: Education, Annual Personal Income & Sexual Orientation (N =50)



Reasons for Disclosure: Unburdening Stress and Wanting Resources

- "When I found out I was HIV positive, it hit me hard man...I was going mad. I didn't sleep for one whole week...man it was crazy. I couldn't take all that stress. I needed to tell someone--someone that I can trust and count on. One day, I decided what the hell, I will just let my family know."
- "Wow, having HIV/AIDS...It's a difficult cycle...; it destroys you. So uh keeping all that emotion inside you can make you sick. Find someone that you feel that you can trust to take some stress off your shoulders ."
- "I don't like keeping anything away from my friends and my family. ... sometimes I also believe that emotionally I needed support in dealing with this. I felt that they had a right to know. I have several good years of my life left ahead of me not telling them would leave me a feelings of guilt."
- "I tell people just to take burden off my shoulders. Because you're sitting around feeling sorry for yourself, somebody has got to understand so I tell somebody. That's the main reason, just to make my burden a little lighter. So, I tell and let people make whatever they want to make of it."

Reasons for Non-Disclosure: Calculating Social Stigma as Risk Factor Influencing Non-Disclosure Decision

- "I have to be very careful of the people that I share my private information with. ...very careful of my social circle. I have to make sure that I take ownership of who I tell It's almost like you have to become an artist. Because of the stigma that still surrounds the disease, one has to be concerned about how to, when and who to tell about their HIV status."
- "Oftentimes I do not tell people that I am HIV positive because some people cannot accept who you are. You don't want to be treated any differently or for them to worry about are you going to be around tomorrow. It has been such a hurting disease for family members too."
- "I'm very selective because I get this idea that with the HIV that I will be discriminated against and that I will get bad reactions from people and I'm just afraid of the whole rejection."
- "I don't tell people about my disease because of ..shame and guilt and not wanting the extra burden of being made to feel worse than what you're already feeling. I get a lot of the, 'Oh, I'm sorry,' and people are shocked somewhat when they find out."

Mode and Strategies Used in Disclosing HIV Status to Others

- "I am usually very open with my family and friends about my status. But it's very hard when you meet new people in your life to bring that up. It's hard to make yourself vulnerable to opening up to people because you never know if those people would treat you negatively."
- "When I meet someone new, I try to figure out how and when I'm going to tell them. Trust is key. If I'm going to be in a relationship with them I know they need to know; but an ordinary friendship, maybe I can hold back on some of detail things until maybe they've confided something that they too consider to be a secret that they need to tell me."
- "Okay, my virus does not meet a person. If it comes up in a topic of discussion I feel that's my personal life unless you're in my life. If you're in my life, then I will tell you. But if I'm just meeting you, we don't have anything to talk about medically because you don't meet my virus. You meet me as a person."

Conclusions and Implications

- As with other diseases or social conditions, balancing boundaries between private and public spheres is important. However, disclosure to a confidant may lead to obtaining needed health care and social services.
- Providers might urge HIV-positive clients to seek active social support (.e., disclosing to others who might help them).
- Provide and continually reinforce culturally appropriate HIV prognosis information for urban African American males.
- Deliver targeted one-on-one social support for urban Black males in emotional and psychological need following an HIV positive diagnosis.
- Narrative analysis is a useful research strategy for uncovering patients' concerns, fears, expectations and factors related to self-care

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