

# **FROM THEIR OWN PERSPECTIVES, WHY ARE OUT-OF-CARE HIV-INFECTED AFRICAN AMERICAN MSM OUT OF CARE?**



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# **MOST HIV TREATMENT CASCADE DEPICTIONS SHOW A LARGE DROPOFF IN CARE RETENTION EVEN WHEN INITIAL LINKAGE WAS MADE**

**Between one-third and one-half of persons diagnosed with HIV infection in the United States are not receiving regular medical care.**

**Treatment continuum analyses typically show their sharpest drop at the point of retention, especially long-term retention in care.**

**This includes persons who drop out of care or otherwise become lost.**

**However, there is also a very large number of PLH in the United States, many not recently diagnosed, who are living in the community, are not in care (and may never have been), and who are unknown to the surveillance and care system until they become very ill.**

**THE FULL PUBLIC HEALTH IMPACT  
OF TREATMENT-AS-PREVENTION WILL BE  
ACHIEVED ONLY WHEN A HIGH PROPORTION  
OF ALL PLH IN THE COMMUNITY  
ARE ENGAGED TO ENTER OR RE-ENTER CARE**

**To date, care linkage efforts have primarily been focused on those newly-diagnosed with HIV infection.**

**Most efforts to date to re-engage PLH into care have focused on those who very recently missed appointments.**

**In the United States, these efforts primarily affect the 50,000 persons per year with new incident infection.**

**The much larger number—at least 300,000 Americans—who are in the community, have tested HIV+, but are not regularly in care, are not well understood.**

# **AFRICAN AMERICAN HIV+ MSM ARE DISPROPORTIONATELY LIKELY TO BE OUT OF CARE, NOT BE ON ART, AND NOT BE VIRALLY SUPPRESSED**

**HIV infection in the United States has always fallen along sharp lines of disparity related to sexual orientation and race.**

**The sharpest disparity of all is for racial minority MSM. African American MSM have HIV incidence and prevalence rates far higher than any other segment of the US population, a trend that has grown even more pronounced over the years.**

**Few individual-level behavioral characteristics distinguish between racial minority and nonminority MSM.**

**Instead, attention has focused on social and sexual network characteristics of minority MSM, and on viral suppression and infectivity.**

# **AFRICAN AMERICAN MSM ARE MORE LIKELY THAN OTHERS TO HAVE UNDIAGNOSED HIV INFECTION AND—IF INFECTED—LESS LIKELY TO BE IN CARE AND ACHIEVE VIRAL SUPPRESSION**

**Prior research has shown that the sexual partnerships of African American MSM are most likely to be with other racial minority men, that sexual networks are smaller, and that—because HIV is more prevalent—racial minority men are more likely to have HIV+ partners.**

**Rates of undiagnosed HIV infection are higher among Black than nonminority MSM. If infected, racial minority men are less likely to be in HIV medical care, to take and adhere to ART, and to be virally suppressed.**

**This contributes to disparities for HIV-related illnesses and deaths, and also to continuing high disease incidence among African American MSM.**

**But, why are out-of-care racial minority MSM out of care? One very direct approach to answering this question is by asking them.**

# **IN OUR OTHER STUDIES WITH OUT-OF-CARE PLH, SEVERAL FACTORS HAVE EMERGED**

- **Care system infrastructure barriers (hard to get care, bureaucratic systems for appointments, fragmented services, confidentiality concerns)**
- **Beliefs that treatment is needed only when you are sick or have illness symptoms**
- **Treatment is a constant negative reminder of illness and HIV status**
- **Interference due to substance abuse, life chaos, and more immediate life stressors**

# **THE CURRENT STUDY**

**We recruited a sample of African American MSM in Milwaukee who were screened for eligibility:**

- Age 18 or older**
- Tested HIV+ at some point in the past**
- Had not received any HIV medical care for >6 months**

**Participants were recruited from the community using a variety of methods:**

- Announcements placed on web sites used by racial minority MSM**
- Announcements in print media reaching minority MSM as well as in venues such as house balls and clubs**
- Persons referred by DOH linkage to care specialists**
- By chain referral of already-interviewed participants**

**30 out-of-care African American HIV+ MSM are being interviewed. Data presented are from in-depth interviews already transcribed, coded using MAXQDA software, and analyzed.**

# **BARRIERS TO HIV MEDICAL CARE ENGAGEMENT: MAJOR THEMES**

- **Lack of awareness about available care resources**
- **Interference due to substance use and mental health issues**
- **Negative experiences and expectations concerning doctors**
- **Medications as a reminder of HIV status**
- **Stigma, confidentiality, and privacy concerns**



## **LACK OF AWARENESS ABOUT AVAILABLE CARE RESOURCES**

**“It’s been about a year [since I’ve seen a doctor] only because of there have been some financial issues...Because of the deductibles and things, I just try to start spanning it out as much as I could. I just have to ration out my expenses you know...I lost my job and I lost my insurance, so I was going regularly when I had insurance...”**

# **INTERFERENCE DUE TO SUBSTANCE USE AND MENTAL HEALTH ISSUES**

**“I started drinking and doing drugs right extremely heavily at [the time of my HIV diagnosis]...So, it was probably about 10 years... and that’s when I decided...I better start to try to live.”**

**“I can’t take [HIV] medicine when I’m drinking, so I’d rather not take it...That’s what they say with the HIV [medications]. You can’t mix them.”**

**“Well, the drugs had brought me to my knees and I know if I didn’t handle my addiction first that I couldn’t deal with the rest of it.”**

# **NEGATIVE EXPERIENCES AND EXPECTATIONS CONCERNING DOCTORS**

**“Well, I hate those (hospital name) doctors, and nurses and staff, they are distant and it’s like they make you wait for hours and then when they get back to you, you are out of there within 5 or 10 minutes, and they send you home and you are still feeling like crap, you know what I mean? I’ve had too many family members die at (hospital name).”**

**“After initially being admitted from the emergency room...the doctor told me, ‘I’ve only seen this type of infection in people with HIV or AIDS. Would you like to be tested?’...He came back a couple of days later and I’m expecting him to come back by himself and it had to be at least 9 or 10 young interns...I’m thinking they are going to give me a death sentence [when] the doctor walks in with all these people.”**

**“I got to a depressed mode and, you know, I stopped going to see [my doctor].”**

# **MEDICATIONS AS A REMINDER OF HIV STATUS**

**“It’s a reminder every time I take them pills, it reminds me that I got AIDS. I didn’t want to be reminded. I’m feeling good, feeling great and then all of a sudden, the alarm goes off and I want to go off the medication...It was psychologically driving me so bad... So, I stopped.”**

# **STIGMA, CONFIDENTIALITY, AND PRIVACY CONCERNS**

**“You don’t want it [HIV+ status] to get out in the community, it’s very vicious...You were treated like, you know, an enigma that can’t be touched and definitely no coughing.”**

**“Because there was a lot of stuff going on with the gay community...I didn’t want to see nobody I knew there [at the HIV clinic] because I didn’t want nobody else going around telling everybody that they had seen me at that type of place.”**

# **IMPLICATIONS**

**Few prior studies have approached the question of why racial minority MSM are out of care by asking them. Needs identified include:**

- Integrated HIV medical, substance abuse, and mental health services**
- Countering misconceptions about HIV medical care**
- Creating low-threshold medical care delivery convenient, accessible, non-bureaucratic, and affirmative towards HIV+ African American MSM**
- Countering stigma and increasing social supports for HIV+ racial minority men**
- Engaging HIV+ African American MSM in the process of developing these services and programs.**