

Treatment journey of black African women in London: A qualitative exploration of factors that influence initial uptake and adherence to antiretroviral therapy



Authors
Dr Renee West, Positive East
Dee Wang, Spectra CIC
Emma Jones, METRO Charity

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and Dr Rageshri Dhairyan, Consultant Physician
Photos from Freepik



Who is the GMI Partnership?

This study was conducted by the GMI Partnership which is a collaboration of 3 London-based HIV prevention and support charities – METRO Charity, Positive East and Spectra CIC. They provide pan-London, community-based sexual health services to diverse communities across London, including but not limited to the LGBTQ+ and black, Asian and other racially minoritized groups.

Introduction

- + Continuous adherence to antiretroviral therapy (ART) is essential for effective HIV management
- + Understanding the reasons behind the initial uptake and adherence can help tailor support for black African women living with HIV in London
- + The aim of this study is to explore the factors that influence the initial uptake and adherence among black African women living with HIV in London

Methods/Description

- + **Sampling frame** Positive East/GMI Partnership networks
- + **Data collection methods** Semi-structured interviews
- + **Analysis** Thematic analysis
- + **Ethics** Pre-interview information and consent forms
- + **Study limitations** Recall and social acceptability bias, only participants who are engaged in community care and are currently on ART

Participants

- + 26–65 years old; lived with HIV for 4–27 years
- + At least 9 were born outside the UK
- + All were following ART treatment at the time of the study



Results

Reasons for having an HIV test

Severity of symptoms, no improvement with other treatments, pre-natal testing, A&E testing, partner/family diagnosed with HIV/STI.

“ I went to the hospital, that’s where I was referred to go for the [HIV] test. Because they did all the other tests [including an endoscopy and found nothing] and then because my diarrhoea was not stopping. Then I went for the [HIV] test, **that’s when I was told the result.** ”

Aged 56–65, 20 years LHIV



Factors influencing ART initial uptake and re-start

Severity of illness, other health concerns including pregnancy and safety of baby, family responsibilities, cultural beliefs/ stigma, immigration status, housing insecurity, support from friends, family and health care providers.

Factors that influence stopping of ART

Side effects, difficulty intaking, mental health, stigma and discrimination, stressful living conditions, misinformation, gender dynamics and inequalities, travel to visit family and friends, immigration status, social status and lack of support network.

“ [My husband] said, ‘It’s okay, but don’t take the medication.’ And he told me, ‘These people, they aren’t giving for black people this and that.’ ... ‘**Don’t take it,** because they aren’t giving you medication,’ and ‘No, you don’t have HIV.’ So, I just stopped. ”

Aged 56–65, 21 years LHIV

Supportive factors that facilitate initial uptake and adherence of ART

Family and friends, community organisations and integrated/holistic social and healthcare systems.

“ ...Some women [at the charity] were looking good and I was very envious, you know, very confused that they were also HIV positive, and then they talked to me, ‘Oh, we are positive as well. **As long as you can take your medication properly and you eat well, don’t worry, you’ll be okay.** We’ve been there like you.’ I’ve always said, that the peer support I think helped me a lot. ”

Aged 56–65, 27 years LHIV

Reactions to HIV diagnosis

Shock, shame, denial, anger, depression, suicidal ideation, inability to perform daily tasks, non-disclosure of diagnosis.

“ I was so shocked because I wasn’t sick at all...that embarrassment made me leave that workplace...depression kicked me so hard. I didn’t tell anyone. **It was my own journey, my silent journey.** I even changed my phone number. I lost all my friends because I didn’t want to be known again. ”

Aged 56–65, 14 years LHIV

“ Because even when my sister passed away, even I wanted to die, but when **I saw her children, her kids, they needed someone.** Yes. So, I called them because when the funeral time, when I was there, and they say, ‘Auntie, Auntie, please stay with us. Don’t go, don’t leave us.’ So yes, because of the children. ”

Aged 46–55, 12 years LHIV

Conclusions

- + Interplay of emotional, social and structural factors influences treatment initiation and adherence
- + Support networks are crucial to facilitate adherence and address psychosocial needs
- + Holistic, tailored person-centred, interventions to paramount to facilitate engagement
- + Research on the impact of social determinants on testing and ART adherence

The success of the PURPOSE1&2 trial (of 6-monthly lenacapavir injectables) is a mind blowing achievement for succeeding with the goal of zero transmissions by 2030.

It is particularly important for women whose lives are unstable – due to housing insecurities, being pregnant and breastfeeding, have family responsibilities, and imbalanced gender dynamics, such as those of the women in this study.

Now let us take their stories and ensure that no one, no woman, no girl is left behind! Let us advocate together, that not only us in the global north, but those in the global south, have equitable access to HIV diagnosis, prevention (including PrEP), treatment and on-going support.

#WeAreNotDoneYet
#PutPeopleFirst

Find out more about our work: positiveeast.org.uk