

Wellbeing of Black African women aged 50 and over living with HIV

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Background

Research with women aged 50 and over living with HIV has considered the impact of several areas of physical, psychological, and social wellbeing. Due to socioeconomic and health disparities experienced by Black African people, negative outcomes of living with HIV are exacerbated. However, research and theoretical frameworks of living and ageing with HIV do not specifically concern the experiences of Black African Women Living with HIV (WLWH). Research has also not exclusively considered the views that Black African WLWH have about their current wellbeing, or about their future wellbeing in ageing with HIV. This study therefore aimed to address the question: *how do Black African women over 50 living with HIV view their current and future wellbeing?*

Methods

Eight participants aged 50 years and over, who self-identified as cis-female and as Black African were recruited from a HIV clinic. Participants had been living with HIV for at least 5 years, and had an undetectable viral load at the time of interview. Participants attended an online or in-person interview, where they were asked questions about their current and future wellbeing. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA), to draw together and interpret themes from interviews. An expert by experience who met inclusion criteria for this study was consulted to develop the interview questions, and study materials.

Findings - Six key themes were developed from interview analysis:

(1) **Adjusting to living with HIV** – participants described a process of having adjusted to living with HIV over time, with some reaching a state of acceptance and others still experiencing disbelief about their diagnosis.

"You have to let it go, because if you, if you keep, you know, looking backwards it just gonna dragging you and you never, never gonna take that step forward"

(3) **Ways of coping changed over time** – participants explained how they coped and maintained their wellbeing differently when they were first diagnosed compared to now. For some, peer groups were helpful at the beginning. For others, learning to focus on the present moment, or feeling distracted by caring/maternal roles, helped maintain psychological wellbeing in the present.

"... so those are the kind of things I like to do um, just keep me busy, to be active ..."
"... so I was able to rise above all this, because I have these two children and their wellbeing was also on my head"

(5) **Living with HIV in the future** – for some participants, thinking about living with HIV into the future caused anxiety. However, some participants felt that ageing with HIV will not affect them any differently than ageing without HIV.

"... I have thought about um, if I'm gonna age quicker because of it [HIV], and I've only thought that because of you know the fatigue and stuff ... now that I'm in my 50's"

(2) **HIV prevented meeting long-term hopes and goals** – participants described how living with HIV had stopped them from having children, pursuing romantic relationships and/or pursuing jobs they wanted.

"... you remember I told you about um, HIV robbed me of my ambitions"
"... you've had hopes for children and you're like, so I'm not gonna have children because of four bottles? [referring to HIV medication] Nobody's gonna look at me again like ... a potential?"

(4) **The impact of living with HIV changed over time** – participants described how the impact of medication side effects became less severe over time, as treatment developed and improved. The impact of living with HIV on social wellbeing continued over time though, and participants observed and experienced HIV-related stigma from non-HIV healthcare professionals.

"they're [medications] much more effective, you know and since, er, since you know however many years ago, 10 years ago ... things have moved along"

(6) **Cultural beliefs about HIV increased fears of being judged** – participants described how culturally-influenced negative beliefs about HIV increased fears of being judged by others.

"but those are the kind of stigmas I went through where you're always an object of shame or reproach or they just wanna cover you up so you don't look like you're dying you know"

Implications

These findings have possible implications for medical and psychological care for Black African WLWH aged 50 and over. HIV-related stigma was described by participants across multiple themes, with negative effects on their social, sexual, and psychological wellbeing. These effects were exacerbated for the WLWH interviewed in this study, given the additional effects of stigma intersecting with being members of an ethnic minority. Education for WLWH, non-HIV healthcare professionals, and people not living with HIV could therefore help in addressing and overcoming HIV-related stigma.

Peer support groups were also described as helpful for some participants for adjusting to living with HIV. For other participants though, fears of being judged and of people in the community 'finding out' meant adapting, limiting, or 'compartmentalising' social circles, and therefore avoiding peer groups. There is therefore an implication as to how Black African WLWH are invited to peer groups. For example, there could be a role for HIV professionals (e.g. psychologists) in completing 'pre-group' work to help address internalised and anticipated stigma which could be preventing group attendance.

Finally, there are clinical implications relating to the uncertainty and anxiety expressed by participants towards ageing with HIV. It could be helpful for WLWH aged 50 and over to be provided with information about what to expect in ageing with HIV, as further research in this area progresses. For example, if HIV medication is known to affect health-related changes in ageing with HIV. This could help in addressing the anxiety associated with the uncertainty of ageing with HIV expressed by participants in this study.

Conclusions

Although the sample size was small and from one recruitment site, findings from this study provided insight into the experiences of Black African WLWH aged 50 and over. This study has highlighted several possible implications for medical and psychological clinical practice to help promote the overall wellbeing of Black African WLWH aged 50 and over.

Findings also have implications for further developing HIV theory and research. For example, it is recommended that future research consider how to support Black African WLWH in overcoming HIV-related stigma which could be preventing access to peer support, or other support which could promote their wellbeing.

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References

- Earnshaw, V. A. & Chaudoir, S. R. (2009). From conceptualising to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS and Behavior*, 13(6), 1160-1177.
- Geronimus, A. E. (1996). Black/white differences in the relationship of maternal age to birthweight: a population-based test of the weathering hypothesis. *Social science & medicine*, 42(4), 589-597.
- Gu, Y., Gu, S., Lei, Y. & Li, H. (2020). From uncertainty to anxiety: how uncertainty fuels anxiety in a process mediated by intolerance of uncertainty. *Neural Plasticity*. <https://www.frontiersin.org/journal/10.3389/fnpls.2020.00638>
- Machtiger, E. L., Wilson, T. C., Haber, J. E., & Weiss, D. S. (2012). Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS and Behavior*, 16(8), 2091-2100.
- Moss-Morris, R. (2013). Adjusting to chronic illness: time for a unified theory. *British Journal of Health Psychology*, 18(4), 681-686.
- Rubtsova, A. A., Wingood, G., Ofotokun, I., Mehta, C. C., Gustafson, D., Vance, D. E., Sharma, A., Adimora, A. A. & Holstad, M. (2021). Psychosocial mechanisms of self-rated successful aging with HIV: a structural equation model. *AIDS and Behavior*, 25(9), 2875-2885.



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