"I was scared dating... who would take me with my status?"- Living with HIV in the UTT era in Johannesburg, South Africa

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BACKGROUND: Despite South Africa's rollout of Universal Test-and-Treat (UTT) in 2016, many people living with HIV (PLHIV) still experience gaps in ART uptake, adherence, and retention. We sought to understand how PLHIV perceive their HIV status in the UTT era, if there are any challenges, and how their experiences differ from individuals diagnosed with HIV at earlier stages of the epidemic

METHODS: As part of an ongoing randomized controlled trial, in May 2021, we conducted in-depth interviews with 27 adult (≥18 years) PLHIV referred by HIV counsellors at three peri-urban primary healthcare clinics and three focus group discussions (N = 27) with PLHIV recruited by snowball sampling through civil society organisations in Johannesburg, South Africa. Interviews and focus group discussion were audio-recorded, transcribed verbatim, translated to English, and analysed thematically.

RESULTS: Despite HIV and ART knowledge being more ubiquitous and ART more accessible, patients still reported feelings of guilt and shame and challenges with accepting their HIV diagnosis. Some of the self-stigma patients reported was related to transmissibility. Many participants associated their diagnosis with their own reckless or irresponsible behaviour, with some expressing a desire to identify the person who infected them, i.e. someone else to blame. Participants also expressed fears of transmitting HIV to others. There was a sense of "HIV prevention altruism" as participants felt the responsibility to protect their loved ones. They seemed to perceive themselves as a threat to other people and avoided sexual relationships or chose relationships with other PLHIV to avoid the anxiety of potentially infecting others. They considered whether to risk rejection, avoid relationships, or avoid disclosure and felt they had limited options. Further, fears and anxieties of rejection persisted despite being on HIV treatment, leading to adherence challenges due to perceived risk of unintended disclosure. Additionally, knowledge of treatment-as-prevention, i.e. that ART leading to viral suppression eliminates risk of transmission, was low.

CONCLUSION: Despite the normalization of HIV within communities, transmission-related self-stigma persists. Disseminating information on treatment-as prevention could reduce the psychological burdens of HIV including self/internal stigma, encourage disclosure, and remove barriers to HIV testing, treatment uptake, and adherence.

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