

1 “I was scared dating... who would take me with my status?”- Living with HIV in the 2 UTT era in Johannesburg, South Africa

3 Tembeka Sineke¹, Dorina Onoya¹, Idah Mokhele¹, Refiloe Cele¹, Shubhi Sharma², Smangele
4 Sigasa¹, Mandisa Dukashe⁴, Laila Hansrod⁵, Robert Inglis⁵, Rachel King⁶, Jacob Bor^{1,2,3}

5 6 **Affiliations:**

7 ¹ Health Economics and Epidemiology Research Office, Department of Internal Medicine,
8 School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand,
9 Johannesburg, South Africa

10 ²Department of Global Health, Boston University School of Public Health, Boston, MA, USA

11 ³Department of Epidemiology, Boston University School of Public Health, Boston, MA,
12 USA

13 ⁴HIV Survivors and Partners Network, Tshwane, South Africa

14 ⁵Jive Media Africa, Pietermaritzburg, South Africa

15 ⁶Institute for Global Health Sciences, University of California, San Francisco, USA

16 **Correspondence:** tsineke@heroza.org

17 **Keywords:** UTT, PLHIV, U=U, TasP

18

19

20

21

22 **ABSTRACT**

23 **BACKGROUND:** South Africa rolled out Universal Test-and-Treat (UTT) in 2016,
24 extending treatment eligibility to all persons living with HIV (PLHIV). Through this study,
25 we sought to understand the experience of people living with HIV in the UTT era in South
26 Africa.

27 **METHODS:** In May 2021, we conducted in-depth interviews (IDI) (N = 27) with adult (≥ 18
28 years) PLHIV referred by HIV counsellors at three peri-urban primary healthcare clinics. We
29 also conducted three focus group discussions (FGDs) (N = 27) with adult PLHIV recruited
30 from clinics or from civil society organisations through snowball sampling. Follow-up
31 interviews were conducted with 29 IDI and FGD participants, to gain a deeper understanding
32 of their journey living with HIV. Participants were asked to reflect on their HIV diagnosis,
33 what their HIV status meant to them in light of the UTT era and how, if at all, being HIV-
34 positive affected their lives. Interviews and focus group discussions were audio-recorded,
35 transcribed, translated to English, and analysed thematically.

36 **RESULTS:** The study included 4 men and 23 women recruited from clinics and 12 men and
37 16 women recruited from civil society (total N= 54). Participants reported that PLHIV could
38 live a long life with antiretroviral therapy (ART) and that ART was widely accessible.
39 However, they reported that HIV elicited feelings of guilt and shame as a sexually
40 transmitted disease. Participants used the language of “blame” in discussing HIV
41 transmission, citing their own reckless behaviour or blaming their partner for infecting them.
42 Participants feared transmitting HIV to others and felt a responsibility to avoid transmission.
43 To manage transmission anxieties, participants avoided sexual relationships, chose HIV-
44 positive partners, and/or insisted on using condoms. Many participants feared – or had
45 previously experienced – rejection by their partners due to their HIV status and reported
46 hiding their medication, avoiding disclosure to their partners, or avoiding relationships

altogether. Most participants also reported having low to no knowledge about treatment-as-prevention (TasP). Participants who were aware of TasP expressed less anxiety about transmitting HIV to others and greater confidence in having relationships.

CONCLUSION: Despite the normalization of HIV as a chronic disease, PLHIV still experience transmission anxiety and fears of rejection by their partners. Disseminating information on treatment-as-prevention could reduce the psychosocial burdens of living with HIV, encourage open communication with partners, and remove barriers to HIV testing and treatment adherence.

INTRODUCTION

HIV/AIDS was imbued with social meaning from its earliest days, as people sought to understand this new, mysterious, and lethal condition. In 1981, United States public health officials infamously linked AIDS to four already-stigmatized “risk groups” – homosexuals, heroin users, haemophiliacs, and Haitians. As Susan Sontag wrote, AIDS diagnosis became a metaphor for indulgence, deviance, and transgression, a stigma or a mark of personal failure [1]. In sub-Saharan Africa (SSA), different metaphors emerged based on epidemiological and cultural contexts. AIDS was linked to sex work, witchcraft, divine punishment for sinful acts, and attributed to immorality [2-7]. The negative social meaning associated with HIV was rooted in real fears of early death, leaving loved ones behind, and contagion. Stigma, however, has been profoundly injurious to the mental health of people living with HIV (PLHIV) and has discouraged HIV testing, status disclosure, and treatment and prevention uptake [8-14].

Antiretroviral therapy (ART) has transformed HIV/AIDS into a clinically-manageable chronic disease with limited impact on life expectancy [15] and economic productivity roles [16, 17]. South Africa rolled out ART in the public sector in 2004, and approximately 5.1

71 million people were on therapy and virally suppressed in 2020[18]. Access to ART is
72 widespread, with 96% of South Africans living within 10km of a health facility providing
73 ART [19]. As of September 2016, all PLHIV are eligible for ART regardless of CD4+
74 lymphocyte count, under South Africa’s Universal Test-and-Treat (UTT) policy [20, 21].

75 Even though HIV is no longer viewed as a death sentence; HIV remains stigmatized [22-24].
76 A recent survey of young adults in rural South Africa found that 78% did not feel
77 comfortable having a sexual relationship with someone who was HIV positive even if they
78 were on ART [25]. These data are perhaps surprising given that people with HIV who are
79 virally suppressed cannot transmit the virus sexually. Although the scientific basis for HIV
80 treatment-as-prevention (TasP) was established in 2011, TasP has not historically been
81 emphasized in HIV counselling in South Africa [26], resulting in low knowledge of TasP [25,
82 27]. Evidence from other contexts suggests that providing information on TasP, including the
83 “Undetectable Equals Untransmittable (U=U)” message may alleviate stigma and improve
84 self-image among PLHIV [28].

85 In this qualitative study, we sought to understand how PLHIV in Johannesburg, South Africa,
86 experience and interpret their HIV status in the UTT era; how being HIV-positive affects
87 their lives; and what role, if any, knowledge of TasP plays in their experience of living with
88 HIV. Understanding the meaning ascribed to HIV and the challenges PLHIV face due to their
89 status is critical to support psychosocial well-being and to motivate testing and ART
90 adherence.

91 **METHODS AND MATERIALS**

92 **Study design**

93 This qualitative study was undertaken as formative research to guide the development and
94 randomized evaluation of an intervention to integrate U=U/TasP into HIV counselling in

95 South Africa (NIH R34 Bor/Onoya)[29, 30]. The larger project aims to determine whether
 96 informing patients about HIV treatment-as-prevention during HIV post-test and adherence
 97 counselling affects their knowledge and attitudes; stigma and wellbeing; as well as towards
 98 ART uptake and adherence. This formative research study consists of in-depth interviews and
 99 focus group discussions with PLHIV residing in and around Johannesburg, South Africa.
 100 Data was collected in May 2021.

101

102 **Data collection**

103 Adults (≥ 18 years) living with HIV were recruited from peri-urban primary healthcare clinics
 104 in Johannesburg for participation in in-depth interviews. Potential participants were identified
 105 and referred by lay HIV counsellors. Trained study staff screened potential participants who
 106 were well enough to provide written informed consent in the participant's preferred language.
 107 In addition, participants consented to have the findings written and published in scientific
 108 papers as part of the research work. Interviews lasted approximately 45 minutes and were
 109 conducted in a private space within the clinic. In-depth interviews covered the following
 110 domains: 1) perceptions of and experiences with HIV diagnosis (including thoughts and
 111 feelings after diagnosis, experiences with disclosure, and impact on relationships with family,
 112 friends and sexual partners), 2) In-depth understanding of challenges PLHIV experienced
 113 related to their HIV status and 3) perceptions about TasP. Interviews were conducted in
 114 English, Sotho and Zulu.

115 We also conducted three focus group discussions (FGDs). Participants for two of the FGDs
 116 were recruited through snowball sampling, starting with ART-experienced members of a civil
 117 society organisation that advocates for U=U/TasP in Johannesburg, South Africa. These
 118 FGDs were stratified by gender to promote open dialogue among participants around topics
 119 involving sexual relationships. A third FGD consisted of younger (**Table 1.**) and recently

120 diagnosed participants recruited from clinics. The FGDs were facilitated by trained study
121 staff and lasted for approximately two hours, covering similar topics to in-depth interviews
122 including, experiences with the HIV diagnosis, experiences with HIV treatment, perceptions
123 about treatment-as-prevention, and questions around communication methods for U=U/TasP.

Table 1. Characteristics of patients included in the analysis

	Key informant interviews N=27 (col%)	Focus Group Discussions round 1 N=21 (col%)	Focus Group Discussions round 2 N=6 (col%)
Age at enrollment			
18 - 30	24 (88.9)	N/A	6 (100.0)
30+	3 (11.1)	21 (100.0)	N/A
Gender			
Females	23 (85.1)	9 (42.9)	6 (100.0)
Males	4 (14.9)	12 (57.1)	N/A
Recruitment source			
Civil society organisation	N/A	21 (100.0)	6 (100.0)
Primary health facility	27 (100.0)	N/A	N/A

1

2 **Data analysis**

3 Interviews and focus group discussions were audio-recorded, transcribed verbatim, translated
4 to English, and analysed thematically. Data were analysed according to the following
5 themes:

- 6 1. Meaning ascribed to HIV and PLHIV self-image in the UTT era
- 7 2. Challenges PLHIV experience related to their HIV status, particularly regarding
8 relationships and disclosure and regarding treatment adherence
- 9 3. Understanding of U=U/TasP and its role in self-image and relationships

10 Major trends and cross-cutting themes were identified and then refined over several meetings.
11 To maintain confidentiality and anonymity, all identifiers were removed from the final
12 analytic data. This study was approved by the Human Research Ethics Committee (Medical)
13 of the University of the Witwatersrand (M200529 MED20-05-019) and Boston University
14 Medical Campus Institutional Review Board (H-40891).

15 **RESULTS**

16 **1. Meaning ascribed to HIV and PLHIV self-image in the UTT era**

17 1. Increased normalization of HIV

18 HIV was seen as “normalized” by most participants. And majority of the participants knew
19 many people who were living with HIV. Treatment was ubiquitous, and HIV was no longer
20 viewed as a death sentence. Many participants had friends and family members on ART,
21 living healthy, normal lives:

22 *“I can’t stop taking my medication because I am HIV positive, a lot of people are*
 23 *living normal lives, I’m not the only person and I’m not the first one.” –Female, 18-*
 24 *25yrs, key informant interview*

25 Participants did not view HIV as a death sentence with treatment widely available. Direct
 26 experience of family and friends having success with ART gave people confidence that they
 27 too could live a normal life with HIV:

28 *“I have a younger sibling who was born with the virus from my parent, my sibling has*
 29 *been taking the treatment ever since. That is what gave me some motivation that if*
 30 *they could live for so long and be healthy then that means I can also do the same.” –*
 31 *Female, 18-25yrs, key informant interview*

32 Despite the normalisation of HIV, participants reported feelings of guilt and shame related to
 33 their HIV diagnosis. In some cases, these feelings led to challenges in coping and accepting
 34 their HIV status and to delays in ART initiation:

35 *“To be honest I was never okay, I even started drinking a lot and I didn’t take the*
 36 *treatment from September, October, November I think I only started taking the*
 37 *treatment in February this year.” –Female, 18-29yrs, key informant interview*

38 *“Umh like really, truly speaking; at first I was really disappointed as I am not that*
 39 *type who is busy dating all the time. I have one partner but then I learned to accept*
 40 *because I have kids, I had to tell myself that I have to live for their sake”.- Female,*
 41 *26-30yrs, key informant interview*

42 *"I didn't know how to feel. It was two different stories: I was pregnant and I was*
 43 *HIV+. For me, I felt disappointed, but then, I was just thankful I was still alive."*-

44 ***Female, 26-30yrs, key informant interview***

45 1.2. Persistent HIV stigma is linked to sexual transmission

46 Despite the waning association of HIV with death, HIV still remained highly stigmatised as is
 47 often associated as a sexually transmitted disease. In addition to self-judgment, participants
 48 worried about the judgments of others. Being labelled as HIV-positive brings the most
 49 intimate aspects of one's life into the public eye as HIV status disclosure involves the loss of
 50 privacy and control over information about one's own private life and health. This
 51 internalized stigma negatively impacted acceptance of the diagnosis, with participants citing
 52 feelings of guilt and shame for contracting the virus. Some participants viewed their HIV
 53 diagnosis as an indicator of moral transgression. Participants described HIV transmission
 54 using the language of blame. Some blamed themselves for acting irresponsibly, while others
 55 blamed their partners, using language suggesting that HIV transmission indicated a breach of
 56 trust. One participant mourned her loss of virginity because of the resulting HIV infection,
 57 voicing anger and frustration that she was not more "disciplined":

58 *"I started treatment in 2017 because I was in denial, was hiding it even at home, this*
 59 *thing and was scared to talk about this situation. Ok to think about it, the fact that I*
 60 *break my virginity when I was 21 isn't. It means I had to discipline myself, thinking*
 61 *that you know what, unfortunately at the time I was breaking my virginity I got*
 62 *pregnant and I got HIV and it was so sad to me that I disciplined myself for such a*
 63 *long time I was well disciplined for this. I had -anger, I didn't take treatment" –*

64 ***Female, FGD, civil society group***

65 Another respondent blamed herself for what she felt was reckless behaviour and felt a strong
66 motivation to avoid onward transmission:

67 *"I took a risk, after taking that risk with my partner I saw him presenting HIV*
68 *symptoms I knew it there and then that he is HIV positive because he had Shingles. So*
69 *I don't want to infect someone else"* –**Female, 18-25yrs, key informant interview**

70 Participants described experiencing feelings of indignation at the carelessness of partners
71 who did not try harder to protect them from HIV. They consequently felt a strong sense of
72 responsibility to be careful and avoid transmitting HIV to others. Not having someone else to
73 blame led to feelings of shame and forced people to reckon with their own role in
74 transmission. Regardless of who was responsible in a given instance, a key theme was the use
75 of language connoting culpability and blame.

76 *"most embarrassing thing is not knowing who gave it to me... if I had someone to*
77 *blame,... "but now I'm taking accountability... I was careless and don't have anyone*
78 *to blame"* - **Female, 26-30yrs, key informant interview**

79 Transmission was interpreted as a breach of trust within a relationship.

80 *"I didn't believe it at first because I only had one partner. I trusted that person and I*
81 *didn't expect him to infect me with the virus. I was very confused because we have*
82 *been together for years.... It took me a while to accept it. But as time went on, I ended*
83 *up accepting"* –**Female, 18-25yrs, key informant interview**

84 **2. Challenges PLHIV experienced related to their HIV status regarding relationships** 85 **and disclosure**

86 **2.1. Transmission Anxiety**

87 Although the stigma associated with HIV was linked to transmission, it had broader impacts
88 on how PLHIV perceived themselves and shaped fears for their future. Participants voiced
89 concerns such as “I don’t know what will happen to me” “what the future will bring”. Much
90 of this sentiment derived from the way that HIV shaped people’s experiences with current
91 and future relationships, the topic to which we now turn.

92 Transmission-related HIV stigma had a profound impact on PLHIV’s expectations and
93 experiences of sexual relationships. Participants feared transmitting HIV to their sexual
94 partners, felt responsible for avoiding transmission, and feared being stigmatised by others
95 for being a risk of transmitting HIV to other people. Both men and women feared
96 transmitting HIV to others and that fear weighed on them:

97 *“The only thing that scares me is the possibility of transmitting this virus.”- Female,*
98 *FGD, civil society group*

99 *"I can't sleep with someone without a condom" "I don't want to infect another person*
100 *with this thing" "I am scared [of infecting someone]";- Male, 40+yrs, key informant*
101 *interview*

102 Some participants avoided relationships altogether, others chose future partners based on
103 their HIV status, and others insisted on condom use although this was not always consistent.
104 Some participants avoided relationships, delayed sex, or chose HIV-positive partners to
105 manage anxiety around transmitting HIV to others.

106 *“But for a couple of months, I think I had this anxiety; I believe I still have it even*
107 *now because I would meet someone and then as the relationship progresses, I would*
108 *always run away from the sex talk, whether he is HIV positive or negative. I’ve tried*
109 *dating someone who’s HIV positive, I met him in one of those support groups you get*

110 on Facebook, and with him also I was still not comfortable, ... I used to fear that we
111 would be busy and then he will take it out also, and I don't know what he has; and
112 you know people worry about HIV only and I'm thinking "I can't have two or three
113 STD's", so yeah, it's something I'm still working on, the anxiety! It's still there."-
114 **female, 26-30yrs, key informant interview**

115 Dating other PLHIV was one way participants sought to manage transmission anxiety:

116 "Well, I think I still fear infecting someone else because I still use HIV as a criteria,
117 like a searching criteria so when I look at my list I'm like "Okay God at least he must
118 be HIV positive also", I have blocked the idea of dating someone who's HIV negative
119 in my head because I felt that it's going to be uncomfortable for them whenever I have
120 to take the pill in from of them; if I tell him that "this week I'm going through pill
121 fatigue" they wouldn't understand, instead they would think "You are being selfish,
122 take your pill, you must protect me also". **Female, 26-30yrs, key informant**
123 **interview**

124 One female PLHIV even rejected an HIV-negative partner because she didn't feel
125 comfortable being intimate with him and didn't want to "waste his time".

126 "I remember this one guy who came to my workplace, we met, we had a conversation
127 and he asked me out. Two weeks later, because I felt "I'm falling for this person", I
128 used my [HIV] status to now push him away, and he just said , "So what?" But we
129 broke up because I wasn't ready to get intimate, I just told him "I don't want to waste
130 your time, I don't think I'll be able to be intimate with you anytime soon so I'd rather
131 set you free now"; at first, he could understand, I said no. let me deal with myself first

132 *and then I will try again but for now NO” Female, 26-30yrs, key informant*
 133 *interview*

134 Some participants used condoms to avoid transmission:

135 *"Yes it (relationship) changed. I now realised that I always have to use a condom*
 136 *whenever I engage in sex." - Female, 18-25yrs, key informant interview*

137 *“He does understand but sometimes it becomes a challenge because his work requires*
 138 *him to travel and I am not sure if he complies with his treatment therefore I prefer for*
 139 *us to always use protection.” - female, 18-25yrs, key informant interview*

140 However, condom use was inconsistent, as some participants had partners who did not want
 141 to use condoms.

142 *“He refused to use a condom first of all. Obviously that led to me falling pregnant.*
 143 *Before falling pregnant, I experienced a lot of STI’s. One of them being HPV,*
 144 *Syphilis, Gonorrhoea, I had a whole list of them, that’s what took me to the clinic at*
 145 *the end of the day, at the beginning, before I even fell pregnant. So, I was in and out*
 146 *of the clinic, my parents didn’t even know that I went to the clinic” — female, FGD,*
 147 *civil society group*

148 Others recognized that condoms could not be used if partners were trying to conceive.

149 *"When it comes to my future partner, we will use protection, but when the time comes then he*
 150 *decides we should have a baby, I would then ask him to come with me to the clinic. He will*
 151 *receive counselling, and maybe they will tell him how and what to do." Female, 26-30yrs,*
 152 *key informant interview*

2.2. Reputation, fear of rejection, and challenges finding a partner

Participants expected judgment and rejection from potential partners, friends and their families, and worried that peers would gossip about their status. These fear and negative experiences added to disclosure challenges. Some participants chose not to disclose their status manage fear of rejection, while others saw early disclosure as imperative to identifying and protecting a supportive partner. Disclosure fears also affected ART adherence, as some people felt they had to hide their medication or not take their medication if they were going out with friends. Some PLHIV feared that their HIV status would be weaponized against them via gossip or perceived shaming.

“If sometimes I fight with someone, maybe a relative. They tell you about your status [reveal my status to others], that’s why I don’t want to tell them.” –Male, 40+yrs, key informant interview

Participants bristled at the loss of privacy if their HIV status became known to their peers.

“Some were supportive though some were judgemental, like one of my friends would just ask me randomly “Hey lady do you take your treatment”? I would just respond and say “You are not going to tell me that I must take my treatment because I know my status”- Female, 26-30yrs, key informant interview

Many participants worried that their HIV status would reduce their ability to find relationship partners. These concerns were often based on direct experience including past rejections.

“And I was scared dating... partners rejected me... who would take me [as a partner] with my status”-Female, 26-30yrs, key informant interview

And fear of rejection led some PLHIV to think twice about entering a relationship.

175 *“Right now there is this guy who is showing interest in me. I was still thinking about,*
 176 *if I agree to start a relationship with him, will he understand my situation? I will have*
 177 *to explain my situation to him. I don’t know if he will accept it or will just carry on*
 178 *with his life” – young female FGD, civil society group*

179 Pessimism about finding a supportive partner was associated with a negative future outlook.
 180 Some PLHIV saw key life milestones – having a long-term relationship with a desirable
 181 partner, having children – as out of reach because of their status.

182 *“I don’t want to lie, I am scared because I’m still very young and I don’t know what*
 183 *life has for me, and what kind of partner am I going to find, is he going to accept it or*
 184 *not and also I don’t have a child so I don’t know, I don’t want to lie I really do not*
 185 *know. However, that will never stop me from taking my treatment.” –Female, 26-*
 186 *30yrs, key informant interview*

187 *“At the time I thought I wouldn’t be able to have kids” - Female, 26-30yrs, key*
 188 *informant interview*

189 2.3. Disclosure challenges

190 Disclosing one’s HIV status can be a difficult conversation, and some participants –
 191 particularly younger participants sought to avoid it. For example, one female participant
 192 described “disclosing”, using an indirect method, by taking her medication in front of her
 193 partner, without actually talking about her HIV status or how she and her partner would
 194 navigate it:

195 *“[Our relationship] has changed because we didn’t talk for quite some time. He stays*
 196 *in Durban and at the time I was in the Eastern Cape. We didn’t talk and he didn’t*

197 *want me to visit him. He then decided around December that I can visit him. We never*
 198 *spoke about it, I used to take my treatment in front of him, I don't know if he would*
 199 *hide his or what but I would take mine at the time when I had to. We are okay now, we*
 200 *communicate.” - Female, 18-25yrs, key informant interview*

201 A young male participant describes a similar scenario in which disclosure occurred indirectly
 202 rather than through direct communication. Due to its stigma, HIV remains difficult to talk
 203 about within a relationship:

204 *“. In my past relationship, it happened that my girlfriend was aware that this person*
 205 *is going through this, she saw my tablets but didn't have the guts to ask me. Her*
 206 *friend found a way to ask me and I openly told her friend. After that I realised she was*
 207 *distant..” –Male, 18-25yrs, key informant interview*

208 Older participants, who were likely more relationship-experienced, saw early disclosure as a
 209 critical “screening tool” to select a partner that would support them regardless of their HIV
 210 status:

211 *“On the first day I meet her I tell her I am HIV positive; it will be up to her whether*
 212 *she continues, or she leaves.” –Male, 40+yrs, key informant interview*

213 **3. Understanding of U=U/TasP and its role in self-image and relationships**

214 Our study respondents were recruited from two populations: PLHIV referred from public
 215 sector clinics and PLHIV identified through a civil society organization that works on
 216 TasP/U=U. Most participants recruited from the clinic were not aware, or were not confident,
 217 that ART leading to viral suppression prevents HIV transmission. For example one
 218 participant recruited from the clinic reported:

219 *"Yes I've heard that on Facebook but they said after some time when taking your*
 220 *treatment you can't transmit. But, I don't know how true that is."* - **Female, 26-30yrs,**
 221 **key informant interview**

222 PLHIV who knew about U=U/TasP and had confidence in the science described the feeling
 223 of knowing that they would not infect their partner so long as they stayed on their medication.
 224 The quotes convey a significant reduction in anxiety, the sense of a weight being lifted, and
 225 the way that U=U/TasP opened up opportunities to live a normal life.

226 *"If you stick to your treatment you don't have to worry about infecting your partner.*
 227 *[Being virally suppressed,] I feel normal. I feel like anyone else. I can start a*
 228 *relationship with anyone I want."* **Female, 26-30yrs, civil society group**

229 *"I was so much looking forward to the day when I would find out I was virally*
 230 *suppressed; my goal was to see the VL going down; when it was <40 copies, I knew I*
 231 *couldn't infect someone else. Now I didn't have to worry about HIV"* *"you see a very*
 232 *bright future". [respondent was privy to the science of U=U early because he was in*
 233 *HIV research];"* - **Male, FGD, civil society group**

234 *"I'm not worried about transmitting to someone else because I know that when I'm*
 235 *virally suppressed I can't transmit, and I AM virally suppressed."* -**Male , civil society**
 236 **group**

237 Having information on TasP/U=U also armed PLHIV with the confidence to have more open
 238 conversations about HIV within their relationship.

239 *"I disclosed my status to my baby daddy, and then... he was scared and it was heavy,*
 240 *'cause you know, men are weak. I'm sorry to say that. But men are weak. To*

241 understand that they have fear over a lot of things. He was very much concerned
242 about the child again. But I got information, I educated him about U=U, and how we
243 are going to save the child from getting infected by the virus. I was taking my
244 treatment, I was using the condom when having sex. That was the only thing that
245 saved my child from getting HIV" –**Female, 18-25, key informant interview**

246 Finally, the ability to control transmission risk through daily ART adherence led to a
247 reduction in internalized stigma and the sense that PLHIV could be fully moral actors in the
248 world.

249 "being virally suppressed means I'm a full human again; HIV is no longer an issue;
250 what is for me is to keep it suppressed;...I didn't feel comfortable shaking hands initially, but
251 now ...I can really stand up and just be myself; I can talk about HIV without feeling like I'm a
252 victim".- **Male, FGD, civil society group**

253 **DISCUSSION**

254 This paper aimed to look at how do PLHIV experience their HIV status in the UTT era and
255 whether the meaning of HIV evolved as the epidemic matured. We conducted interviews and
256 focus groups with PLHIV in Johannesburg, South Africa, in May 2021 to better understand
257 contemporary experiences of people living with the virus.

258 While many participants view HIV as “normal”, due to the availability of life-saving ART
259 and increased visibility of PLHIV, transmission-related stigma still remains pervasive. Our
260 findings echo those of other studies that have found that stigma remains prevalent despite the
261 scale up of treatment [31, 32]. This is particularly concerning as studies have shown that
262 stigma negatively impacts testing for HIV, a barrier to ART adherence and is associated with
263 depression among PLHIV [33, 34]. Consequently, these problems ultimately undermine
264 efforts towards the elimination of HIV [35] and the stigma associated with it.

HIV stigma is often internalized, leading to continued psychosocial harm [6]. Our findings show that study respondents reported feelings of shame and guilt for contracting the virus and perceived their infection as a moral transgression. These findings are consistent with prior research in sub-Saharan Africa, which showed that HIV infection was perceived to be a result of risky sexual behaviour [2, 7].

Alongside the shame of contracting HIV, respondents felt a deep responsibility to avoid transmitting the virus to others. Respondents reported fear and anxiety around transmission as a major concern. Prior literature suggests that PLHIV are deeply concerned about transmission and engage in a variety of behaviours to protect partners from infection, a phenomenon known as “HIV prevention altruism” [36]. To manage transmission anxiety, participants avoided relationships, avoided sex, choose to date other PLHIV, or insisted on condom use. These results are consistent with previous findings whereby individuals reported diminished sexual desire due to fears of transmitting HIV to others [37, 38]. Engaging in preventive behaviors to limit transmission represented an important zone of “moral agency” for PLHIV. For those who knew about TasP/U=U, the ability to effectively prevent transmission through daily ART adherence was tremendously freeing and an important burden lifted.

Another major concern was fear of rejection, which manifested in disclosure challenges. Some participants chose to conceal their status due to fear of judgement and stigma from their family, friends and/or partners. In some instances, indirect disclosure of HIV status occurred despite participants efforts to conceal status. Non-disclosure due to stigma can result in additional challenges for PLHIV including interruptions in treatment and can negatively impact quality of life [39]. Conversely, several studies show that individuals who disclose their status are more likely to receive support from their loved ones and are more likely to adhere to treatment [40]. Fear of rejection was also linked to internalized stigma,

with several participants conveying that partners would be well within their rights to reject them because they were HIV-positive, implying that they perceived themselves to be a less worthy partner than someone who was HIV-negative.

Most participants in our study did not have knowledge of TasP/U=U and this is consistent with recent empirical work from South Africa [25, 27] and a global systematic review [28]. In our study, the only participants that were knowledgeable about TasP were those recruited from a civil society organization that does advocacy work on TasP/U=U. These participants expressed that they were no longer worried about infecting their partners. Moreover, they felt confident disclosing their status to others because they knew that they could not infect someone else. And they no longer feared rejection because their partners had no good reason to reject them.

Our findings underscore the significant extent to which messaging on TasP/U=U may address the significant hardships experienced by PLHIV due to persistent transmission-related stigma, anxiety and shame. It is therefore paramount to ensure that U=U/TasP information is disseminated widely [41] as it offers an opportunity to reduce stigma and discrimination against PLHIV [42]. The message of U=U/TasP offers people the opportunity to exercise their moral agency, to have full lives with families, sex, and relationships without feeling like they are a threat to others. Equipping PLHIV and the society at large with sufficient knowledge is a powerful tool to eliminate misinformation and break the cycle of stigma.

The results should be considered in light of several study limitations. First, the study population is not representative of the general population. Our study was conducted in a predominantly peri-urban urban setting with only a few health facilities included. The study is subject to potential bias due to some of the participants recruited via referrals. In particular, the participants who were knowledgeable about TasP/U=U were identified through a U=U

advocacy organization and may have had greater confidence in TasP than other persons knowledgeable of the science. We also did not explicitly recruit groups of people that are at higher risk for HIV acquisition including members of the LGBTQIA+ population, sex workers, and people who inject drugs. Despite these limitations, we were able recruit a study population via purposive sampling that was diverse in terms of gender, age and level of U=U/TasP knowledge. Second, although we reached saturation in our key themes, the sample size was limited, and this study may need to be replicated in other settings and augmented by quantitative surveys to further establish generalizability. Third, coding/analysis of qualitative data is subjective. To mitigate the impact of potential rater bias, we had at least two coders (TS, RC, JB) code all transcripts and held detailed discussions to reconcile differences in codes and interpretation.

CONCLUSION

Persistent stigma in the UTT era is rooted in the sexual transmission of HIV. PLHIV experience self-stigma related to their status, experience anxiety about transmitting HIV to others, and fear rejection from partners based on their HIV status. Disseminating information on TasP/U=U could reduce the psychosocial burdens of HIV including self/internalized stigma, encourage disclosure, and remove barriers to HIV testing and treatment adherence.

ACKNOWLEDGEMENTS

The authors would like to thank the members of the HIV Survivors and Partners Network, and the Prevention Access Campaign.

REFERENCES

1. Sontag S. AIDS and its metaphors. The disability studies reader. 1997:232-40.

- 336 2. Campbell C, Nair Y, Maimane S, Nicholson J. Dying Twice' A Multi-level Model of
337 the Roots of AIDS Stigma in Two South African Communities. *Journal of health*
338 *psychology*. 2007;12(3):403-16.
- 339 3. Duffy L. Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the*
340 *Association of Nurses in AIDS Care*. 2005;16(1):13-20.
- 341 4. Hartwig KA, Kissioki S, Hartwig CD. Church leaders confront HIV/AIDS and
342 stigma: a case study from Tanzania. *Journal of Community & Applied Social*
343 *Psychology*. 2006;16(6):492-7.
- 344 5. Otolok-Tanga E, Atuyambe L, Murphy CK, Ringheim KE, Woldehanna S.
345 Examining the actions of faith-based organizations and their influence on HIV/AIDS-
346 related stigma: a case study of Uganda. *African health sciences*. 2007;7(1):55-60.
- 347 6. Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A. Internalized
348 stigma, discrimination, and depression among men and women living with HIV/AIDS
349 in Cape Town, South Africa. *Social Science & Medicine*. 2007;64(9):1823-31.
- 350 7. Wood K, Lambert H. Coded talk, scripted omissions: The micropolitics of AIDS talk
351 in an affected community in South Africa. *Medical Anthropology Quarterly*.
352 2008;22(3):213-33.
- 353 8. Bos AER, Onya H. Fear of stigmatization as barrier to voluntary HIV counselling and
354 testing in South Africa. *East Afr J Public Health*. 2008;5(2):49.
- 355 9. Daftary A, Padayatchi N, Padilla M. HIV testing and disclosure: a qualitative analysis
356 of TB patients in South Africa. *AIDS care*. 2007;19(4):572-7.
- 357 10. Grant E, Logie D, Masura M, Gorman D, Murray SA. Factors facilitating and
358 challenging access and adherence to antiretroviral therapy in a township in the
359 Zambian Copperbelt: a qualitative study. *AIDS care*. 2008;20(10):1155-60.

- 360 11. Izugbara CO, Undie C-C, Mudege NN, Ezeh AC. Male youth and Voluntary
361 Counseling and HIV-Testing: the case of Malawi and Uganda. Sex Education.
362 2009;9(3):243-59.
- 363 12. Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, et al. Impact of
364 HIV-related stigma on treatment adherence: systematic review and meta-synthesis.
365 Journal of the International AIDS Society. 2013;16:18640.
- 366 13. Mabunda G. Voluntary HIV counseling and testing: knowledge and practices in a
367 rural South African village. Journal of Transcultural Nursing. 2006;17(1):23-9.
- 368 14. Weiser SD, Heisler M, Leiter K, Percy-de Korte F, Tlou S, DeMonner S, et al.
369 Routine HIV testing in Botswana: a population-based study on attitudes, practices,
370 and human rights concerns. PLoS medicine. 2006;3(7):e261.
- 371 15. Johnson LF, Mossong J, Dorrington RE, Schomaker M, Hoffmann CJ, Keiser O, et al.
372 Life expectancies of South African adults starting antiretroviral treatment:
373 collaborative analysis of cohort studies. PLoS medicine. 2013;10(4):e1001418.
- 374 16. Bor J, Tanser F, Newell M-L, Barnighausen T. In a study of a population cohort in
375 South Africa, HIV patients on antiretrovirals had nearly full recovery of employment.
376 Health affairs. 2012;31(7):1459-69.
- 377 17. Camlin CS, Charlebois ED, Getahun M, Akatukwasa C, Atwine F, Itiakorit H, et al.
378 Pathways for reduction of HIV-related stigma: a model derived from longitudinal
379 qualitative research in Kenya and Uganda. Journal of the International AIDS Society.
380 2020;23(12):e25647.
- 381 18. UNAIDS. Country factsheets South Africa 2020 [Available from:
382 <https://www.unaids.org/en/regionscountries/countries/southafrica>.
- 383 19. Forum South African Private Practitioners Forum. Quality of HIV care higher in
384 clinics than hospitals 2021 [Available from: <https://sappf.co.za/news/413964>.

- 385 20. NDoH. National Policy on HIV Pre-exposure Prophylaxis (PrEP) and Test and Treat
386 (T&T). Pretoria: National Department of Health. 2016.
- 387 21. NDoH. Fast tracking implementation of the 90-90-90 strategy for HIV, through
388 implementation of the test and treat (TT) policy and same-day anti-retroviral therapy
389 (ART) initiation for positive patients. Pretoria, South Africa: National Department of
390 Health (NDoH) 2017.
- 391 22. Chan BT, Tsai AC. HIV stigma trends in the general population during antiretroviral
392 treatment expansion: analysis of 31 countries in sub-Saharan Africa, 2003–2013.
393 JAIDS Journal of Acquired Immune Deficiency Syndromes. 2016;72(5):558-64.
- 394 23. Horter S, Bernays S, Thabede Z, Dlamini V, Kerschberger B, Pasipamire M, et al. “I
395 don’t want them to know”: how stigma creates dilemmas for engagement with treat-
396 all HIV care for people living with HIV in Eswatini. African Journal of AIDS
397 Research. 2019;18(1):27-37.
- 398 24. Kalichman SC, Mathews C, Banas E, Kalichman MO. Treatment adherence in HIV
399 stigmatized environments in South Africa: stigma avoidance and medication
400 management. International journal of STD & AIDS. 2019;30(4):362-70.
- 401 25. Bor J, Bärnighausen T, Tanser F, Barofsky J, Flanagan D. Life plans of young adults
402 in rural KwaZulu-Natal: intervention study. Forthcoming. 2018.
- 403 26. Mabuto T, Mshweshwe-Pakela N, Ntombela N, Hlongwane M, Wong V,
404 Charalambous S, et al. Is HIV Post-test Counselling Aligned with Universal Test and
405 Treat Goals? A Qualitative Analysis of Counselling Session Content and Delivery in
406 South Africa. AIDS and Behavior. 2021;25(5):1583-96.
- 407 27. Bor J, Musakwa N, Onoya D, Evans D. Perceived efficacy of HIV treatment-as-
408 prevention among university students in Johannesburg, South Africa. Sexually
409 transmitted infections. 2021;97(8):596-600.

- 410 28. Bor J, Fischer C, Modi M, Richman B, Kinker C, King R, et al. Changing knowledge
411 and attitudes towards HIV treatment-as-prevention and “Undetectable=
412 Untransmittable”: A systematic review. *AIDS and Behavior*. 2021;25(12):4209-24.
- 413 29. RePORT N. Integrating U=U into HIV counseling in South Africa (INTUIT-SA)
414 2020 [Available from:
415 https://reporter.nih.gov/search/Ek4tFJQaLE6aKgl6hX1l_g/project-details/10082738.
- 416 30. RePORT N. Integrating U=U into HIV counseling in South Africa (INTUIT-SA)
417 2021 [Available from:
418 https://reporter.nih.gov/search/Ek4tFJQaLE6aKgl6hX1l_g/project-details/10227801
- 419 31. Mojola SA, Angotti N, Denardo D, Schatz E, Xavier Gómez Olivé F. The end of
420 AIDS? HIV and the new landscape of illness in rural South Africa. *Global Public*
421 *Health*. 2022;17(1):13-25.
- 422 32. Viljoen L, Bond VA, Reynolds LJ, Mubekapi Musadaidzwa C, Baloyi D, Ndubani
423 R, et al. Universal HIV testing and treatment and HIV stigma reduction: a
424 comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial
425 in South Africa and Zambia. *Sociology of Health & Illness*. 2021;43(1):167-85.
- 426 33. MacLean JR, Wetherall K. The Association between HIV-Stigma and Depressive
427 Symptoms among People Living with HIV/AIDS: A Systematic Review of Studies
428 Conducted in South Africa. *Journal of Affective Disorders*. 2021;287:125-37.
- 429 34. Mall S, Middelkoop K, Mark D, Wood R, Bekker L-G. Changing patterns in
430 HIV/AIDS stigma and uptake of voluntary counselling and testing services: the
431 results of two consecutive community surveys conducted in the Western Cape, South
432 Africa. *AIDS care*. 2013;25(2):194-201.

- 433 35. Assembly UG. Political declaration on HIV and AIDS: on the fast-track to accelerate
434 the fight against HIV and to end the AIDS epidemic by 2030. New York: United
435 Nations. 2016.
- 436 36. King R, Katuntu D, Lifshay J, Packel L, Batamwita R, Nakayiwa S, et al. Processes
437 and outcomes of HIV serostatus disclosure to sexual partners among people living
438 with HIV in Uganda. *AIDS and Behavior*. 2008;12(2):232-43.
- 439 37. Siegel K, Schrimshaw EW, Lekas H-M. Diminished sexual activity, interest, and
440 feelings of attractiveness among HIV-infected women in two eras of the AIDS
441 epidemic. *Arch Sex Behav*. 2006;35(4):437-49.
- 442 38. Wamoyi J, Mbonye M, Seeley J, Birungi J, Jaffar S. Changes in sexual desires and
443 behaviours of people living with HIV after initiation of ART: implications for HIV
444 prevention and health promotion. *BMC Public Health*. 2011;11:633.
- 445 39. Simbayi LC, Kalichman SC, Strebel A, Cloete A, Henda N, Mqeketo A. Disclosure of
446 HIV status to sex partners and sexual risk behaviours among HIV-positive men and
447 women, Cape Town, South Africa. *Sexually transmitted infections*. 2007;83(1):29-34.
- 448 40. Atuyambe LM, Ssegujja E, Ssali S, Tumwine C, Nekesa N, Nannungi A, et al.
449 HIV/AIDS status disclosure increases support, behavioural change and, HIV
450 prevention in the long term: a case for an Urban Clinic, Kampala, Uganda. *BMC*
451 *Health Services Research*. 2014;14(1):1-11.
- 452 41. Bor J, Onoya D, Richman B, Mayer KH. A Failure to Disseminate Transformative
453 Science-HIV Treatment as Prevention, 10 Years On. *The New England journal of*
454 *medicine*. 2021;385(25):2305-7.
- 455 42. Coyne R, Noone C. Investigating the effect of undetectable=untransmittable
456 message frames on HIV stigma: an online experiment. *AIDS Care*. 2022;34(1):55