

## Test but not treat: community members' experiences with barriers and facilitators to universal antiretroviral therapy uptake in rural KwaZulu-Natal, South Africa

Article (Accepted Version)

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1 **Test but not treat: Community members' experiences with**  
2 **barriers and facilitators to universal antiretroviral**  
3 **therapy uptake in rural KwaZulu-Natal, South Africa**

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25

26 **Keywords:** Test and Treat, ART uptake, barriers, facilitators, Stigma

27

## 28 **Abstract**

## 29 **Introduction**

30 Antiretroviral therapy (ART) has revolutionised the care of HIV-positive individuals  
31 resulting in marked decreases in morbidity and mortality, and markedly reduced transmission  
32 to sexual partners. However, these benefits can only be realised if individuals are aware of  
33 their HIV-positive status, initiated and retained on suppressive lifelong ART. Framed using  
34 the socio-ecological model, the present study explores factors contributing to poor ART  
35 uptake among community members despite high acceptance of HIV-testing within a  
36 Treatment as Prevention (TasP) trial. In this paper we identify barriers and facilitators to  
37 treatment across different levels of the socio-ecological framework covering individual,  
38 community and health system components.

## 39 **Methods**

40 This research was embedded within a cluster-randomised trial (ClinicalTrials.gov, number  
41 NCT01509508) of HIV treatment as Prevention in rural KwaZulu-Natal, South Africa. Data  
42 were collected between January 2013 and July 2014 from resident community members. Ten  
43 participants contributed to repeat in-depth interviews whilst 42 participants took part in repeat  
44 focus group discussions. Data from individual interviews and focus group discussions were  
45 triangulated using community walks to give insights into community members' perception of  
46 the barriers and facilitators of ART uptake. We used thematic analysis guided by a socio-

47 ecological framework to analyse participants' narratives from both individual interviews and  
48 focus group discussions.

## 49 **Results**

50 Barriers and facilitators operating at the individual, community and health system levels  
51 influence ART uptake. Stigma was an over-arching barrier, across all three levels and  
52 expressed variably as fear of HIV disclosure, concerns about segregated HIV clinical services  
53 and negative community religious perceptions. Other barriers were individual (substance  
54 misuse, fear of ART side effects), community (alternative health beliefs). Facilitators cited by  
55 participants included individual (expectations of improved health and longer life expectancy  
56 following ART, single tablet regimens), community (availability of ART in the community  
57 through mobile trial facilities) and health system factors (fast and efficient service provided  
58 by friendly staff).

## 59 **Discussion**

60 We identified multiple barriers to achieving universal ART uptake. To enhance uptake in  
61 HIV care services, and achieve the full benefits of ART requires interventions that tackle  
62 persistent HIV stigma, and offer people with HIV respectful, convenient and efficient  
63 services. These interventions require evaluation in appropriately designed studies.

## 64 **Introduction**

65 Antiretroviral therapy (ART) provides individual health benefits through a reduction in  
66 morbidity and mortality (1, 2) and public health benefits through prevention of HIV  
67 transmission (3-5). These successes coupled with other effective HIV prevention tools (6)  
68 make the elimination of HIV possible and highlight the importance of pursuing universal  
69 health coverage for all in order to achieve this goal (7). Although, many mathematical models  
70 have shown that it is possible to eliminate HIV with universal testing and immediate ART,  
71 these assumptions have been challenging to replicate at the population level even in well-  
72 resourced clinical trials (8-10). One of these trials, the ANRS 12249 TasP trial tested this  
73 hypothesis of universal testing and immediate ART in rural KwaZulu-Natal, South Africa,  
74 but failed to demonstrate a reduction in HIV incidence (11). This null finding was largely  
75 attributable to poor linkage to care resulting in limited ART uptake observed during the trial  
76 (12, 13).

77 The majority of qualitative studies exploring the factors enhancing and preventing ART  
78 uptake and the HIV care continuum were conducted in the era when CD4 thresholds were  
79 used to signal eligibility for starting ART (14-17). These previous studies have shown that  
80 expanding ART eligibility can increase ART uptake, but not all patients that had ART-  
81 eligible CD4 counts initiated therapy (18). A systematic review of published data from  
82 studies in sub-Saharan Africa looking at retention in HIV care from 2000-2011 showed that  
83 approximately one third of eligible patients were lost prior to ART initiation (19). Despite the  
84 increase in ART availability, HIV-related stigma continues to be a barrier to engagement in  
85 care (20) . Improved testing, linkage, and ART initiation procedures coupled with stigma  
86 reduction interventions are still needed to achieve the UNAIDS 90-90-90 targets to test 90%

87 of people living with HIV (PLHIV), initiate 90% onto treatment and ensure viral suppression  
88 of 90% of those people (18, 21).

89 Studies using qualitative data collection methods investigating factors that facilitate and  
90 hinder ART uptake in the test and treat era have been embedded within the public health  
91 system. Findings suggest that poor staff attitudes, long waiting times and distance to clinics  
92 are barriers to seeking care (22-24). During the TasP trial, care was provided in purpose-built  
93 research clinics, complemented by mobile units in the 22 communities where the trial was  
94 implemented. Despite a high community acceptance of home-based HIV testing, only 30% of  
95 newly diagnosed individuals linked to care within 6 months of HIV diagnosis with an overall  
96 population ART coverage of 51% at the end of the trial (11). We used qualitative methods to  
97 investigate the reasons for this poor uptake of ART, which was a lower proportion than that  
98 reported by other test and treat trials nested within traditional health systems (25-27). We  
99 frame our analysis using the socioecological model to show the embedded levels of influence  
100 from the individual to the local community and wider health system which affect a person's  
101 interactions with health care, specifically HIV-related care (28, 29). The socioecological  
102 model is described using nested circles that place the individuals at the centre, surrounded in  
103 our conceptualisation by the community (the interactions with local services, including  
104 traditional healing systems, in the neighbourhood, for example) situated within the wider  
105 health system which shapes local health care (30). Using this model in our analysis  
106 highlighted the interactions across the different levels that had an impact on ART uptake by  
107 individuals in the TasP trial.

## 108 **Methodology**

### 109 **Setting**

110 The ANRS 12249 TasP trial was a cluster-randomized trial (ClinicalTrials.gov,  
111 number NCT01509508) implemented in 22 clusters from March 2012 to June 2016 to  
112 investigate the impact of ART regardless of CD4 count on population HIV incidence in the  
113 Hlabisa sub-district in rural KwaZulu-Natal (11). This is a rural setting with scattered  
114 homesteads and an estimated HIV prevalence of 30.5% (11). Migration is high in this setting  
115 (31), marriage is uncommon (32) and only 10% of adults are employed (11). Socio-economic  
116 challenges such as a high unemployment rate and high levels of poverty, coupled with  
117 sociodemographic factors such as poor educational attainment, high mobility and migration,  
118 have contributed to high HIV prevalence (33). The use of both biomedical and traditional  
119 healing systems is common in this setting (29).

120 The trial protocol has been described previously [12] but, in brief, control arm participants  
121 identified as HIV-positive were offered ART according to the South African guidelines (CD4  
122 count  $\leq 350$  at trial start [2012], then CD4 count  $\leq 500$  from January 2015). Those in the  
123 intervention arm were offered ART regardless of CD4 count. Participants living with HIV  
124 were referred to dedicated TasP trial clinics within their cluster up to a 45-minute walk for  
125 those farthest from their clinic. The qualitative data used in this study came from two control  
126 arms and two intervention arms, in which HIV care was provided from mobile clinics  
127 attached to mobile/park homes. In addition to providing HIV care, the clinics also catered for  
128 other healthcare needs of the participants living with HIV such as management of diabetes,  
129 hypertension and other ailments. However, no antenatal care was provided. Participants could  
130 opt to receive care from the public primary health care (PHC) clinics where ART would be  
131 prescribed according to national guidelines.

132



## 133 **Study design**

134 This study was nested within four of the 22 clusters in the TasP trial from Jan 2013 to July  
135 2014. We used qualitative methods that included focus group discussions (FGDs), in-depth  
136 interviews (IDIs) and participant observations, to explore issues related to access to health  
137 care, how HIV/AIDS is managed, as well as local practices that facilitate or hinder HIV  
138 testing, ART initiation, and adherence in the context of TasP (34). Using a combination of  
139 repeat focus group discussions (FGDs) (35), repeat semi-structured individual interviews  
140 (IDIs) with the same participants (36, 37) and participant observations (38) enabled us to  
141 determine whether participants' perceptions or experiences regarding regular and repeat HIV-  
142 testing changed or remained the same over time as well as to understand community social  
143 norms. Observations from community walks (38) gave more insight into the perceptions and  
144 experiences of community members and complemented narratives obtained in IDIs and  
145 FGDs.

146

## 147 **Study sample**

148 Overall, we conducted 16 FGDs and 29 IDIs. We purposefully selected individuals for FGDs  
149 in four groups, one in each trial cluster to capture diverse interpretations, divided as follows:  
150 (i) younger adults (18-35-years, mixed gender, n=15) who were randomly recruited; (ii)  
151 older adults (aged >30, mixed gender, n=16) randomly recruited with assistance from a local  
152 community care giver; (iii) mixed ages (18–65-years, including two traditional health  
153 practitioners, n=11) recruited with assistance from a local community member who worked  
154 in a crèche; and (iv) traditional health practitioners (THPs) (aged >35, mixed gender, n=9)  
155 who were recruited using a snowballing technique. The HIV status of these participants was

156 not known to the facilitator, and recruitment was not stratified according to whether  
157 individuals were in care in the TasP trial or not. FGDs lasted 45-120 minutes and were  
158 conducted in community venues, including school halls.

159 IDIs were conducted with 20 participants (10 men, 10 women; aged 17–64 years). Ten of the  
160 participants were interviewed once, randomly identified by approaching their homesteads in  
161 the four trial clusters and interviewed in their homesteads. The other 10 participants were  
162 interviewed repeatedly at three time points with (n=4 males/n=6 females). Five of the  
163 participants were recruited in TasP trial clinics by announcing the existence of the study in a  
164 waiting area of the clinic prior to engaging potential participants individually in order to  
165 purposefully include participants with a known HIV status. The remaining five were recruited  
166 by randomly approaching households across the trial clusters. Repeat interviews were  
167 conducted either at the participants' home or TasP clinic, depending on the participants'  
168 choice and lasted for 30–60 min. All IDIs and FGDs participants were reimbursed an amount  
169 of ZAR 50 (\$5) for transport and all FGD participants were provided with a lunch pack  
170 (juice, fruit and sandwich) after each meeting.

171

## 172 **Data collection**

173 One of the authors (TZ), a social scientist trained in qualitative data collection and a first  
174 language *isiZulu* speaker, the local language of the participants, facilitated both interviews  
175 and FGDs, audio recorded, transcribed verbatim and translated all data into English.

176 Participants who took part in the FGDs were given cameras during the community walks to  
177 capture images of what they considered barriers or facilitators to HIV testing, treatment,  
178 adherence and retention in care. The research facilitator did not interfere with the process of  
179 capturing images and only asked questions for clarity to capture field notes.

180 In both IDIs and FGDs, data were collected to understand participants' perceptions on  
181 healthcare services and their utilisation within study communities, including the utilisation of  
182 TasP trial clinics, understanding of the TasP concept, local practices to support HIV testing  
183 and early ART initiation, and lastly, barriers and facilitators to HIV testing, early ART  
184 initiation and adherence.

185

## 186 **Data analysis**

187 Translated data were discussed by the first author with two co-authors (RC, TZ) specifically to  
188 understand the dynamic interactions between individual, community and health facility level  
189 facilitators and barriers to ART uptake. In this study, we focused our analysis on the individual,  
190 community and health system levels of the socioecological model, relevant translated data were  
191 extracted manually into an Excel spreadsheet as an initial step to coding. Coded data were  
192 repeatedly reviewed by CI, RC and TZ to determine common elements and patterns in the data  
193 and to develop thematic categories in line with Braun and Clarke's thematic analysis approach  
194 (39). Once a satisfactory map of data was achieved, thematic categories were further defined  
195 and refined to identify sub-themes. These were then grouped into individual, community and  
196 health system factors. Data from observation notes were used as an additional source to  
197 strengthen the analyses. Anonymised quotes from some participants were also included in the  
198 manuscript to illustrate certain themes.

199

## 200 **Ethical considerations**

201 The TasP trial was granted ethical approval by the University of KwaZulu-Natal Biomedical  
202 Research Ethics Committee (BREC) in 2011 (Ref: BFC 104/11) and received written informed  
203 consent from all subjects. Further approval was sought for the full protocol developed for the  
204 social science sub-studies, in 2012 (Ref: BE090/12), along with approval from the Community  
205 Advisory Board.

206

## 207 **Results**

### 208 **Characteristics of study participants**

209 Fifty-two participants were enrolled in the study; of whom 36 (69%) were female. The majority  
210 (90%) of the participants were unemployed. Fifteen of the participants attained secondary level  
211 education, 17 attained primary level education and 20 had not received any formal education.  
212 None of the participants attained tertiary level education. The HIV status of all participants in  
213 FGDs was unknown to the facilitator. In individual interviews, the HIV status of participants  
214 recruited from their homesteads was unknown to the facilitator, unless disclosed by participants  
215 during the interview. In repeat individual interviews, one male had an unknown HIV status,  
216 one was HIV negative, two were HIV positive and all six females were HIV positive. One  
217 female participating in repeat individual interviews relocated from the study area and was not  
218 interviewed a third time

219

220

221 **Barriers and facilitators to ART uptake and viral suppression**  
222 **using the socio-ecological model**

223 Our framing of the data using the socioecological framework to describe the barriers and  
224 facilitators to ART uptake at individual, community and health system factors is summarised  
225 in the Figure below.

226 **Figure. Barriers and facilitators to ART uptake and viral suppression using the socio-**  
227 **ecological model**

228

229

230

231

232

233

234

235 **Barriers**

236 *Individual level factors*

237 Individuals avoided visiting the trial clinics for ‘fear of being seen’ by other community  
238 members whilst accessing HIV services:

239 *“there are those who are still not keen. They have a problem that they will be seen at*  
240 *the park home (Trial clinic) and they say that the park home is full of people who have*  
241 *HIV. You see it is something like that. You see there are people who go to the clinic not*  
242 *because they are going to check their own illnesses but they keep looking at the people*  
243 *who are going to the research clinic and they say we are even carrying babies who*

244 *have HIV. Now when a lot of people think about that they think if you go to that clinic*  
245 *you are visible, they wish they can hide from others” (Female, 51 years)*

246 Furthermore, some individuals did not see the need to start treatment as they felt healthy and  
247 had concerns about ART becoming a problem, perhaps due to potential side-effects. One 46  
248 year-old female commented:

249 *“They explained side effects that I may experience when I start treatment. I took*  
250 *treatment and saw my room moving and I cried out loud thinking I was going to die*  
251 *[laughing]. I regretted starting treatment and asked myself why did I do it? They told*  
252 *me that it was going to be for a few days. It was better after some days and I am no*  
253 *longer having side effects.”*

254 Another woman of a similar age, was reticent about giving the reasons for interrupting care in  
255 early interviews, but in the third and final interview she explained the problems she had faced  
256 with side effects:

257 *Ehhh, at the beginning I felt like I was losing my mind. ...I then stopped taking the*  
258 *treatment and I didn't go the following month on the date that they had given me. I*  
259 *said to myself I am stopping these pills if they are going to make me sick. There was*  
260 *a meeting at XX [name of area] and I went to the meeting.... They gave me treatment*  
261 *and I continued taking it. I don't have a problem now.*

262 Other participants taking part in both in-depth interviews and focus group discussions  
263 commented that despite people being counselled not to take ART with alcohol, abuse of  
264 alcohol was a common problem within the community.

265 *“My message will be if they can be educated on the harmfulness of alcohol, they can*  
266 *understand the importance of their lives. Some people will die and leave kids behind*  
267 *just because they preferred drinking alcohol” (Female, 30 years).*

268

269           *“This is a photo of a beer [referring to a photo they had taken during the community*  
270 *observation]. Most people don’t take good care of themselves. Counsellors are*  
271 *educating infected people not to take alcohol with treatment so that treatment can work*  
272 *effectively”* FGD 4 (Youth)

273

### 274 ***Community level factors***

275 Alternative health beliefs are common within Zulu communities and a number of respondents  
276 mentioned these beliefs during the interviews. One participant (female, age unknown but above  
277 65) stated that PLHIV default on treatment because traditional healing sources were easily  
278 accessible and also needed to treat illnesses they believe to have a spiritual origin and as such  
279 utilised frequently as illustrated below:

280           *“They concentrate on using traditional herbs and forget about getting ART. They will*  
281 *continue drinking izichonco (traditional medicine) and stop taking treatment. Izichonco*  
282 *(concoction) are these mixtures that people buy, and they end up not going to the*  
283 *clinic.”*

284 A 35-year-old traditional healer explained during a focus group discussion that they face  
285 challenges in treating PLHIV because they do not disclose their status to them upfront:

286           *“when someone is ill from this (HIV) they run to us (traditional healers), we have a very*  
287 *big challenge. He knows that the illness is eating him away... He asks for me to throw my*  
288 *bones so that I can check with the spirits what may be wrong after telling me that he has*  
289 *idliso [an illness caused through bewitchment]. He is hiding HIV”.*

290 A 57-year old male in the second FGD said women go to the clinic but men prefer to use  
291 traditional medicine:

292           *“If we observe things, like when you are walking around and observing what is going on*  
293           *around the community. You will notice that men do not go to the clinics, there are a few*  
294           *men that go to the clinic on the road, but you will see many women on the road coming*  
295           *from the clinic and you can see that they are sick. Men use traditional medicine more.”*

296 In these communities, health care decisions and choices are influenced considerably by four  
297 main sources: social networks, traditional healing knowledge and beliefs, illness perceptions,  
298 and illness experiences (29).

299 Furthermore, community religious beliefs emerged as a barrier to people engaging early in HIV  
300 care because they are afraid of being judged when they visited health facilities. One participant  
301 during focus group discussion, for example, identified a church during the community walk  
302 and said:

303           *“Churches can be a barrier to test for HIV because you will be regarded as a Christian*  
304           *and not expected to be sexually involved only to find that you are not faithful and have*  
305           *sexual relationships at night. You can be infected but will not be able to visit the clinic*  
306           *since you are known as a Christian” (Male, 21 years).*

307

### 308 ***Health system level factors***

309 Some individuals did not like the fact that the TasP clinics only catered for HIV-positive  
310 patients:

311           *“Most people think that you only visit this clinic when you are infected. That is what*  
312           *they assume most of the time. If you visit this clinic it means that you are infected with*  
313           *HIV” (Female, 46 years).*

314



315 *“The problem with the research clinic is that it is specific for HIV patients. If I visit XY*  
316 *clinic [government clinic] I feel free because I think no one will think that I am going*  
317 *for HIV treatment. The problem starts when you have to go to the park homes (Trial*  
318 *clinics) then you will be associated with HIV or TB. Someone seeing me going to the*  
319 *park homes will say I am taking HIV treatment although it may happen that I was*  
320 *collecting my child’s treatment” (Female, 39 years).*

321 *“Another challenge, like in XY clinic, there is a container (park home) [located in*  
322 *government clinic] and its purpose is known. There are usually girls sitting in queues*  
323 *and it is difficult for a man to go there because people will be asking themselves what*  
324 *I am doing in an HIV clinic” (Male, 22 years at FGD 3 (Youth).*

325

## 326 **Facilitators**

### 327 ***Individual level factors***

328 Participants reported their motivation to stay healthy and expectation of increased life  
329 expectancy as being responsible for their willingness to initiate ART.

330 *“Yes there is something different. When you find out that you are infected and go to the*  
331 *clinic and they give you treatment for HIV, in about 2 months to 3 months you recover*  
332 *and see that you are becoming different, you see that you are getting better. A person*  
333 *can say that I was not like this but now I am looking better because I have started this*  
334 *treatment. That person can continue with the treatment and will have testimony for*  
335 *others to say that you see I was not like this but when I started dedicating my life to*  
336 *treatment my life changed” (Male, 43 years)*

337 Participants were prescribed a single tablet formulation of antiretroviral therapy. This was said  
338 to have facilitated adherence as participants found this easier to take.

339 *“Also that we now have a place where we can have one pill because we do not have one*  
340 *pill in the big (government) clinics. The nurses are also good you can talk to them easily”*  
341 *(Female, 32 years)*

342

### 343 ***Community level factors***

344 Despite the concerns expressed by respondents, cited above, about the mobile trial clinics  
345 being identified as being places where only PLHIV received care, these clinics were viewed  
346 very positively by many community members as it made it easier for PLHIV to access  
347 treatment because they were close to their homes:

348 *“This is the Africa Centre (Trial) clinic. It is helpful because it is nearby and close in*  
349 *the community, it is easy for people to go and collect their treatment. If you miss*  
350 *transport to reach the (Government) clinic you will end up not going to the clinic.”*  
351 *(Male, 21 years)*

352

353 We observed a paradox that while some people, as noted above, feared the trial clinics as  
354 singling out PLHIV, others preferred the model of care in the TasP clinics which catered for  
355 only PLHIV to that of the government clinics which catered for both HIV-positive and HIV-  
356 negative patients. They were more comfortable in the TasP clinics because all attendees were  
357 HIV-positive.

358

### 359 ***Health system level factors***

360 The ‘fast service’ available at the TasP clinics was a big motivation for some which countered  
361 the fact that they might be seen by other people receiving care from clinics meant for only  
362 PLHIV. Despite this fear of being seen by others, PLHIV found the trial clinics to be a ‘non-  
363 judgemental safe place’ as every other person present in the clinic is also HIV-positive.

364

365 *“you don’t wait for a long time and you know that people visiting that clinic are all*  
366 *taking this treatment. In the government clinic, not everyone is taking HIV treatment so*  
367 *they stare at us if we are there for HIV treatment”* (Female, 34 years)

368

369 *“The trial clinics are very convenient because it caters for HIV positive people and*  
370 *there are usually no long queues. Queues are short and everything is very fast. When*  
371 *you go to the research clinic at 8 o’clock, by 8:30 you are done and going back home,*  
372 *but at the government clinic you will only leave at 15h00. It is not the same”* (Female,  
373 35 years)

374

## 375 **Discussion**

376 We used the socioecological framework to examine the barriers and facilitators of HIV  
377 treatment uptake in a healthcare delivery model that provided access to HIV treatment in HIV  
378 care-only trial clinics located in each community. Multiple barriers to treatment uptake were  
379 observed at each level of the socioecological framework, mostly attributable to stigma (fear  
380 of HIV disclosure, concerns about being seen attending HIV-only treatment facilities and  
381 community religious perceptions). This was despite high uptake (92%) of home-based HIV  
382 testing (11). Facilitators of HIV care utilisation included reduced pill burden from single

383 tablet regimens, improved life expectancy on ART and availability of accessible trial clinics  
384 in the community offering a fast and efficient service by friendly staff.

385 Stigma emerged as a dominant over-arching barrier preventing HIV-positive individuals from  
386 accessing care for fear of being seen attending HIV-care only clinics. The same observation  
387 was made another test and treat trial in South Africa and Zambia (40) where people accessing  
388 HIV care in government facilities had to wait in a separate part of the health facility. The  
389 research team noted that ‘being seen’ at the clinic was a major barrier to care utilisation (41).  
390 In our own study, despite this perceived barrier, some individuals actually preferred to visit  
391 the TasP trial clinics because they found the staff to be friendly, and the services to be quick  
392 and efficient. This suggests that the fear of being stigmatised could be overcome for some  
393 people by providing more patient-centred care. This can be achieved by bringing care closer  
394 to the people with a model of care that is multi-morbidity focused and integrated to address  
395 both the concern related to stigma and to geographical accessibility (42, 43). Transitioning  
396 PLHIV as soon as they become stable on ART to adherence clubs or fast-service lane for  
397 three to six monthly drug pick-up has also been shown to improve ART uptake and retention  
398 in care (44, 45).

399 Although PLHIV in the TasP communities were complimentary about the proximity of care  
400 and shorter waiting times made possible by the trial clinics within the community, the  
401 majority of them did not engage with care. The fear of side effects reported by some  
402 participants could be related to the historical use of stavudine and zidovudine during the early  
403 roll-out of ART in this setting, which many people remembered. Providing information to  
404 PLHIV about newer single tablet formulation with fewer side effects could encourage ART  
405 initiation and adherence. It could also be that other competing life issues such as livelihood  
406 sustenance was prioritised over seeking care (22), especially as ‘feeling healthy’ was  
407 mentioned as a reason for delaying care.

408 Some individuals who delay seeking care or who are in denial of their HIV status often visit  
409 traditional healers due to alternative health beliefs (29). This results in poor uptake of ART  
410 and retention in care (46, 47) and consequently increased morbidity and mortality.

411 Community religious perceptions and the judgemental attitudes of Christians emerged during  
412 the community walk as a barrier to accessing HIV services, as people did not want to be seen  
413 by their church members seeking care because of the associated connotations of sexual  
414 immorality (48). The church has also been known to influence HIV care in other ways with  
415 HIV-positive individuals having discontinued their treatment believing they have been cured  
416 of their HIV at their church (49). Such findings illustrate the influence on individuals not  
417 only of local community bodies, such as churches, but also the macro-system which includes  
418 societal, religious and cultural values and influences, within which the health-system,  
419 community and individual levels of our model are embedded.

420 Participants identified substance misuse, especially alcohol, as an emerging problem affecting  
421 engagement in care in both men and women. Alcohol has been shown to be associated with  
422 increased mortality in PLHIV due to poor treatment access and adherence (50).

423 Our findings suggest that to increase ART uptake interventions would have to address stigma  
424 and the time burden of seeking care whilst providing a respectful and efficient service. More  
425 attention will need to be paid to substance misuse such as alcohol and recreational drugs and  
426 their impact on mental health.

427 In our study no one intervention meets the need of all PLHIV, rather differentiated multilevel  
428 interventions targeting stigma at all levels of the socioecological framework would be  
429 required. PLHIV will benefit from the availability of different ART delivery models that they  
430 could choose from depending on their changing personal circumstances.

431 Our research has some limitations. Participants resided in the same community and knew  
432 each other. This could have led to social desirability bias in ways we were not able to capture  
433 during the interviews. Fewer men participated in the study even though they were most likely  
434 not to initiate ART and be retained in care (11, 43, 51). It is unclear whether additional  
435 themes could have emerged if there had been more men in the study. It is also a limitation of  
436 our study that we interviewed HIV-positive individuals who linked to care without  
437 interviewing those who did not link to care to understand their lived experiences.

438 We recognise that clinics serving PLHIV might have resulted to unintentional disclosure,  
439 however, the study aimed to bring HIV treatment and care services closer to patients and to  
440 avoid them being seen in a separate queue at the Government clinic which is the current practice  
441 in local primary health care facilities in the study setting. In IDIs, only one individual declared  
442 their HIV status as unknown, a larger and more inclusive sample may have enabled a  
443 comparison of experiences, attitudes and perceptions of individuals who had tested and knew  
444 their status and those who had never tested.

445 A strength of the study was enabling understanding of HIV-positive individuals behaviour to  
446 accessing care in a model of care that shed light on the trade-offs between accessing a fast  
447 and efficient service provided by friendly staff and the fear of ‘being seen’ in an HIV-only  
448 clinic. This provides a framework to focus interventions to reinforce the facilitators of care  
449 observed within a multi-morbidity context that does not single out HIV.

450 A combination of intervention that addresses the drivers and manifestations of stigma and  
451 impact on mental health, in combination with interventions that alleviate the time and  
452 economic burden of seeking care such as community access to ART could improve ART  
453 uptake and viral suppression in rural South Africa and should be the subject of future  
454 research.

455

## 456 **Competing interests**

457 I have read the journal's policy and the authors of this manuscript have the following  
458 competing interests: CI received honoraria for consulting services and conference attendance  
459 support from Gilead Sciences. All other authors declare that they have no conflicts of interest.  
460 This does not alter our adherence to PLOS ONE policies on sharing data and materials.

461

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478

## 479 **Authors' contributions**

480 CI, TZ, JOG, JL designed and implemented the study. CI, MSi, MSh, JS developed the  
481 research question addressed in this paper. CI, TZ and RC carried out the analysis. CI, RC  
482 and TZ wrote the first draft of the manuscript. All authors contributed to the interpretation  
483 and the presentation of the findings.

484

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646

## 647 **Supporting information**

648 **S1 Table. Barriers and facilitators -Repeat Individual In-depth Interviews**

649 **S2 Table. Barriers and facilitators-Focus Group Discussions and Individual Interviews**

650

