

1 Facilitators and Barriers to Linkage to HIV Care and
2 Treatment among Female Sex Workers in a Community-
3 based HIV Prevention Intervention in Tanzania: a qualitative
4 study

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15 **Abstract**

16 **Background:** HIV-infected female sex workers (FSWs) have poor linkage to HIV care in
17 sub-Saharan Africa.

18 **Methods:** We conducted 21 focus group discussions (FGDs) to explore factors influencing
19 linkage to HIV care among FSWs tested for HIV through a comprehensive community-based
20 HIV prevention project in Tanzania.

21 **Results:** Influences on linkage to care were present at the system, societal and individual
22 levels. System-level factors included unfriendly service delivery environment, including
23 lengthy pre-enrolment sessions, concerns about confidentiality, stigmatising attitudes of
24 health providers. Societal-level factors included myths and misconceptions about ART and
25 stigma. On the individual level, most notable was fear of not being able to continue to have a
26 livelihood if one's status were to be known. Facilitators were noted, including the availability
27 of transport to services, friendly health care providers and peer-support referral and networks.

28 **Conclusion:** Findings of this study underscore the importance of peer-supported linkages to
29 HIV care and the need for respectful, high-quality care.

30 **Keywords:** Sauti project, Linkage to HIV care, Female sex workers, Tanzania, qualitative

31 **Introduction**

32 Linkage to care, defined by the World Health Organisation (WHO) as the first HIV-specific
33 clinical visit (1), is critical for initiation of HIV-related medical, psychological and social
34 services for individuals newly diagnosed with HIV infection. Delays in linkage are associated
35 with lower levels of viral suppression, greater likelihood of viral resistance, increased HIV
36 morbidity, mortality and transmission (2-4). In Tanzania, the HIV Impact Survey (THIS)
37 found that only about 52% of HIV positive adults age 15 and older in the general population
38 had viral load suppression, in part because of delayed or low linkage to care (5).

39 HIV is not uniformly distributed across populations. Given the individual, network-level and
40 structural risk determinants of HIV, key populations such as female sex workers (FSWs) face
41 a disproportionately high risk of HIV infection (6). In Tanzania, FSWs are among the priority
42 populations for expansion of HIV prevention and care services (7). Despite a shift in HIV
43 testing strategy (8), access to HIV treatment and care services among FSWs remains limited
44 (9). Studies conducted elsewhere in SSA have highlighted barriers to linkage to care and
45 treatment among female sex workers including discrimination by hospital staff (10, 11), lack
46 of money for transport (11), and lack of knowledge about HIV treatment centres (12).

47 Sauti program is a PEPFAR-funded program run jointly with the Ministry of Health,
48 Community Development, Gender, the Elderly and Children (MOHCDGEC) through
49 USAID. This community-based HIV combination prevention project, which has been
50 operating in Tanzania since 2015, offers clinical and structural support services to key and
51 vulnerable populations in 14 regions. Services are offered to Sauti beneficiaries through
52 mobile outreach units, operating in hot spots such as truck stops, brothels, bars and mining
53 centres. To ensure improved linkages, Sauti project offered transport support or escorted
54 referral to all FSWs newly diagnosed with HIV infection to nearby health facilities. Peer

55 educators (PEs) and home-based care providers (HBCs) employed by civil society
56 organisations (CSOs) help FSWs' linkage to care through escort to the health facilities.
57 Despite these strategies, not every FSW diagnosed with HIV infection was successfully
58 linked to HIV care.

59 We employ a social-ecological perspective to explore more precisely what factors prevented
60 or facilitated FSWs testing positive in the Sauti Project services to initiate HIV care, with the
61 aim of adapting programs to increase initiation rates. Indeed, a study conducted in Mbeya
62 found that about a third (31%) of individuals testing HIV positive did not link to care for a
63 period of six months (13). An exploration of the barriers and facilitators of linkage to care
64 among FSWs is critical for designing effective interventions to reach national and global
65 goals for HIV control.

66 **Materials and methods**

67 This exploratory qualitative study was conducted in February and March 2017 – the second
68 year of Sauti Project implementation in Tanzania. We conducted participatory group
69 discussions in four regions (Dar es Salaam, Mbeya, Iringa and Shinyanga). These regions
70 were selected because they were among the first regions where Sauti Project rolled-out, had a
71 high number of FSWs compared to other regions in Tanzania (14), and had relatively high
72 HIV prevalence (15). In the study regions, fieldwork took place in wards that were
73 considered of high HIV risk especially those with mines, plantations or highways.

74 **Sampling and data collection**

75 Snowball sampling was used to recruit participants into a group discussion. This strategy was
76 employed due to the highly stigmatised and criminalised nature of sex work in Tanzania. In
77 each region, CSOs staff introduced researchers to three FSWs receiving HIV testing though

78 Sauti Project. These women received information about study aims and procedures and were
79 asked to invite up to three other FSWs receiving Sauti services. Upon reaching a group of 10
80 – 12 participants, the group discussion was conducted. Criteria for participation included
81 being beneficiary of Sauti services, living in the study area, being 18 years or older, reported
82 having received money for sex at least once within the past three months, and provided
83 consent to participate. The main defining socio-demographic characteristics collected were
84 age, education and the venue where individuals' solicited clients. Following data saturation,
85 227 FSWs participated in 21 focus groups.

86 **Procedure**

87 All participatory group discussions were conducted in venues provided by CSOs. The
88 discussion sessions lasted for about 90 – 120 minutes, were moderated by trained researchers
89 and were audio-recorded. Participants were familiar with these settings as CSOs provided
90 HIV-related services including HIV testing and family planning services. Before the
91 beginning of fieldwork, graduate research assistants (RAs) were trained on the protocol,
92 discussion guide and principles of research involving human subjects and informed consent.
93 All RAs were Swahili native speakers and had experience conducting qualitative studies
94 among key and vulnerable populations including FSWs. RAs built rapport with study
95 participants and assumed neutrality by distancing themselves from program implementers
96 (i.e., they declared to the participants that they were researchers and not part of the Sauti
97 Project implementers).

98 A qualitative participatory group discussion guide with open-ended questions was used to
99 facilitate discussion sessions. The discussion guide covered personal experiences with HIV
100 testing services before and during access to Sauti Project services. Themes in the guide
101 included factors that influenced the use of HIV testing and reasons for accepting or avoiding
102 linkage to HIV care facilities.

103 We conducted one participatory group discussion in Dar es Salaam to determine the
104 suitability of the questions asked and practical issues with conducting discussion sessions
105 with FSWs. After it was clear that no significant changes were needed in the guide or
106 procedure, thus the data collected was included in the analysis. During data collection,
107 debriefing sessions were held between research assistants and senior researchers after every
108 group discussion session to discuss the depth of the data collected and emerging issues. We
109 obtained written informed consent from all participants prior to beginning the group sessions.
110 To protect the identity of the participants, we asked them to use pseudonyms during
111 consenting. Numbers were assigned to every participant for reference during discussion.

112 **Data analysis**

113 The audio-recorded interviews were transcribed verbatim. All transcripts were translated into
114 English, entered into QSR NVIVO 10 software (16) and coded by two researchers involved in
115 data collection. A pragmatic approach to analysis was adopted, whereby coders used
116 predefined (anticipated) codes and grounded codes. The predefined codes were developed
117 from the research objectives, prior knowledge and repeated reading of data in early stages of
118 analysis. These codes were further refined through further reading of the data. Grounded
119 codes were developed through a thorough reading of the data by the two researchers in
120 consultation with the data collection team. These codes reflected participants' own language
121 in ways they expressed their ideas. Based on these codes, more conceptual categories were
122 developed and finally into themes. Widely shared views supporting emerging theories were
123 examined alongside deviant cases. In the results, we also present deviant cases as appropriate.
124 Representative quotes illustrating the main findings were identified from various groups.

125 **Ethical considerations**

126 The Medical Research Coordinating Committee (MRCC) of the National Institute for
127 Medical Research (NIMR) in Tanzania (NIMR/HQ/R.8c/Vol.I/432), and Institutional Review
128 Board of the Johns Hopkins University (IRB00006985) approved this study. Approval to
129 work in the study communities was obtained from respective local government offices after
130 authorisation from the regional and district government authorities. All participants
131 completed and provided written informed consent prior to beginning the group sessions.
132 Since sex work is illegal in Tanzania, participants were asked to use pseudonyms during
133 consenting to protect their identity. Numbers were assigned to every participant for reference
134 during discussion. Researchers clearly explained that participation was voluntary and that the
135 participant can decline to participate at any time if she wished to do so. Every attempt was
136 made to minimize biases and ensure the study was conducted in the most ethical manner
137 possible.

138 **Results**

139 **Socio-demographic characteristics**

140 Women who participated in the study were above 18 years old. Over half of the study
141 participants (58.6%) were aged 18 – 23. In terms of education, 59.5% had attained at most
142 primary school education, and the majority reported to solicit their sexual partners through
143 venues, especially in bars, brothels and homes (67.4%). The distribution of ages, education
144 levels and sites where FSWs sought clients are presented in table 1 below.

145 **Table 1: Characteristics of study participants**

Factor	Values/Categories	N = 227 (%)
Age	18-23 years	133 (58.6)
	24+ years	94 (41.4)

Education	Primary school or less	135 (59.5)
	Secondary school or above	80 (40.5)
Sites	Street	48 (21.1)
	Facility-based (bars, brothel & home)	153 (67.4)
	Phone/internet	26 (11.5)

146 **Facilitators of linkage to HIV care among FSW**

147 Participants discussed several factors influencing FSWs' decision to link to care in the Sauti
148 Project implementation sites.

149 **The role of peer-educators**

150 Participants identified peer educators as the primary source of information on available HIV
151 care services through the Sauti Project and facility-based HIV services. According to
152 participants, availability of peer educators encouraged FSWs to go for HIV testing, and it
153 influenced their decision to accept a referral to an HIV care clinic for further services. FSWs
154 reported that when someone is sick, she usually seeks advice from peers about the illness and
155 the peers recommend where to go for medical consultations. For example, the types of
156 services offered, where to get them, whom to contact for help at times of need, and benefits
157 of early initiation of ART.

158 Peer-escorted referral to treatment services was an essential influence on FSWs' decision to
159 accept their first HIV clinical visit to the health facilities. Participants indicated that escorted
160 referral helped clients to receive the service quickly, and made them feel cared. FSWs
161 pointed out that escorted referral increased their confidence and helped to reduce fears,
162 especially during the first HIV clinic visits. For example, in one PGD a participant described
163 that:

164 *The good thing is that the home-based counsellors and peer educators knew the*
165 *service providers, so before you go to the facility, they have already talked to the*
166 *providers and you get the service immediately. However, when you go alone, you get*

167 *many challenges; first, you ask yourself how should I ask about this HIV service*
168 *...[laughs] ... there are many nurses and doctors there...you may end-up leaving*
169 *without seeing them [laughs] ... if you go alone you wait for a long time because no*
170 *one knows you and you are afraid to ask – PGD_2*

171 **Facilitation of transport during the first HIV clinical visit**

172 Participants applauded about transport facilitation to attend the first HIV clinical visit for
173 FSW to minimize some inconveniences e.g. financial constraints to seek services.
174 Participants reported that sometimes FSWs who may have tested HIV-positive or have doubt
175 about their HIV status, fail to present themselves to an HIV care clinic for further HIV
176 services because they cannot afford the transport costs. To them, the facilitation of transport
177 to the clinic was an important motivation for linkage to care.

178 **Presence of project-linked FSW-friendly health care providers at the health facilities**

179 Participants pointed out that the friendly provider-client relationship had a significant impact
180 on linkage to care. Most participants reported that the presence of service providers trained
181 by Sauti Project to provided FSW-friendly services and motivated FSWs to attend HIV care
182 services. According to some FSWs, health workers who received training from the
183 programme were 'less stigmatising', 'knowledgeable about FSWs' health needs',
184 'approachable', and 'confidential'. The importance of the presence of friendly health care
185 providers was emphasised in all PGDs. In one PGD a participant said:

186 *For us (FSWs), it does not matter where you get the service (HIV care services) ...*
187 *what matters is ... does the nurse or doctor understand me? How does she/he look at*
188 *me? If I tell my stories about my clients and my situation [infection], is she ready to*
189 *treat me nicely and will not tell other people that I have the disease [HIV]? –*

190 **PGD_18**

191 **Availability of peer support network**

192 Community engagement through peer educators was a powerful motivator for many FSWs to
193 seek HIV related information and services. Some participants recounted a story about the
194 feelings of social isolation and loneliness when someone receives the HIV-positive diagnosis.
195 *“Testing HIV-positive makes you feel as if you are left alone, and that everyone leaves you*
196 *because of your condition” [PGD_4].* Participants pointed out that, the presence of the Sauti
197 Project and interaction between HIV positive FSWs with peers who had similar situation
198 minimized fear of isolation and revived hopes of living like others even after an HIV-positive
199 diagnosis. Usually, HIV positive FSWs felt less alone and less stigmatised when they met
200 other FSWs with the same HIV status. HIV positive FSWs felt to be part or integrated into
201 the networks of people living with HIV, thus willing to be escorted by their peers to the
202 health facility for treatment and care. A participant during the discussion pointed out that:

203 *“The advantage is that the one who tells you go to the health facility has been through*
204 *the same situation and the same feelings you have, so it becomes easier to accept*
205 *because you know that whenever you have a problem, she can guide you on what to*
206 *do. Also, they know each other; encourage one another ... so you are not alone any*
207 *more”- PGD_1*

208 **Barriers to linkage to HIV care and treatment**

209 The analysis identified barriers to linkage to HIV care that applied to FSWs in the Sauti
210 Project implementation sites. Overall, barriers to linkage to HIV care are presented and
211 discussed in multiple levels namely; system-level, societal-level and individual-level factors
212 framed participants’ discussion on barriers to linkage to HIV care.

213 **System-level barriers**

214 ***Fear of breach of confidentiality***

215 All participants perceived referral to be the services offered to individuals diagnosed with
216 HIV either through peer escort or given self-referral to the nearby health facility for HIV care

217 registration and initiation into HIV care and treatment. Subsequently, in all PGDs,
218 participants reported fear of breach of confidentiality as one of the significant barriers for
219 FSWs diagnosed with HIV to enrol to the health clinic for care and treatment services. FSWs
220 indicated that some healthcare providers working at the clinics “tell other people about their
221 clients’ HIV status”. It was also reported that some of the health workers who were aware of
222 individual positive status "alert their friends not to have sexual relations with the infected
223 FSWs". Participants in one of the PGD sessions echoed this concern:

224 *“... male healthcare providers are leading gossipers ... after attending to you (s) he*
225 *will start to caution his close male friends to take care, ... not to approach us, and*
226 *later everybody in the village will know it [our HIV status]” – PGD_14*

227 Similarly, some participants had mistrust toward some peer educators (PEs) and home-based
228 care (HBC) providers who were instrumental in linking clients to the HIV care clinics. In
229 particular, participants complained that some PEs and HBC providers working with the
230 project disclosed their status, which led to bad naming (called ‘prostitute’) and even
231 discrimination by other community members. Discussing this barrier, some participants
232 pointed out that:

233 *[...] Truly, they [PE and HBCs] help us, but some after they have sent you to the*
234 *health facility you will hear the news about your HIV status everywhere and [...] they*
235 *[community members] will start to refer you as a prostitute” – PGD_8*

236 *"some...not all...if they escort you to the hospital, they end up spreading the*
237 *information to other people that you have the virus” – PGD_21*

238 **Prolonged pre-enrolment period**

239 Participants reported that if one accepted to be linked to HIV care, she was supposed to
240 attend up to three sessions of adherence counselling before enrolment. Most participants felt
241 that attending three days' counselling sessions alerted other community members about their
242 HIV status. Moreover, attending all those sessions needed transport cost and time that could
243 help with something else. Some participants cited cases where clients had attended one or
244 two sessions and decided to abscond. A remark made by a participant in one PGD session
245 explains this sentiment:

246 *“We know of people who were referred to HIV care clinic, but after realising that*
247 *they will have to attend three days' training with other HIV-positive people, they*
248 *decided to abscond [...]. Some do attend [the training] for one or two days [...] you*
249 *know the nurses don't tell you when you will start getting the medicine, so you go*
250 *there the first day, you go to class then you are told to come back next day – there is*
251 *no clear information”* – **PGD_10**

252 ***Vertical and unintegrated HIV service delivery approach***

253 Participants reported that some health facilities had dedicated rooms or blocks to attend for
254 testing and counselling, enrolment to care, and administration of ART. According to
255 participants, people who attend the facility for other general health services could easily see
256 people living with HIV visiting those rooms. Providing services in dedicated venues were
257 perceived to be stressful since it minimises privacy. One FSW who was against offering HIV
258 care and treatment services at dedicated facilities away from other general services said:

259 *“You normally see them [PLHA] congested at one place” ... so when you go there,*
260 *everybody knows that you have that dangerous disease and you become a talk of the*
261 *town”*. – **PGD_5**

262 Many participants reported that some HIV care clinics were open for 8 hours only (from 8 am
263 to 4 pm), and thus could not attend clients who visited the health facilities after that time.
264 Participants suggested that the availability of health providers at the health facility all the
265 time would help to overcome the challenges of working hours. In some districts, participants
266 complained that some health facilities were enrolling clients to HIV care only for a few
267 dedicated days in a week.

268 *“If you go there on days when they do not enrol new people, they just look at you and*
269 *ask you to come another day” – PGD_14*

270 **Societal-level barriers**

271 *Myths and rumours about ARVs*

272 Many participants discussed widespread concerns about the side effects of ARV drugs, and
273 that these rumours discouraged many FSWs from accepting linkage to care. Participants
274 reported that everyone in the community knows that treatment with ARVs can cause
275 horrifying dreams and loss of appetite. In addition, FSWs thought that ARVs could have
276 adverse outcomes including further weakening for people suffering from opportunistic
277 conditions. In some PGD sessions, participants expressed the belief that treatment with ART
278 was behind the increased spate of sudden deaths occurring in the community.

279 *Many people believe that if you start it (ARV) early it makes you tired and makes your*
280 *body to weaken quickly. You can even die suddenly even when you are sleeping... You*
281 *may feel a headache and die suddenly – PGD_21*

282 FSWs who self-identified themselves to have enrolled in treatment complained that ARVs
283 were very powerful and required one to eat well before taking them. For many participants,
284 the ‘strength of ARVs’ and the ‘need to eat well’ caused fear among FSWs who tested HIV
285 positive but who had not started treatment with ART. Following this belief, participants

286 thought it was wise for FSWs to choose whether to take the drugs despite the anticipated
287 adverse outcomes.

288 *“there are times when the family go to bed without food, and now you will know what*
289 *to do with your medicine ... if that is not death”- PGD_9*

290 ***The stigma associated with receiving HIV care.***

291 Almost all participants mentioned HIV stigma as a key barrier for FSWs to successful link to
292 care. Some participants reported having experienced stigma, particularly when they interact
293 with health workers. There were, for example, cases where FSWs reported to have been
294 delayed services or called bad names when visiting health facilities. Participants indicated
295 that it was also common for peers and other community members to use derogative terms and
296 naming toward people living with HIV. According to participants, people who utilised HIV
297 care services were referred to using stigmatising and derogatory terms such as ‘*Maiti*
298 *mtarajiwa*’ [lit. expectant corpse], ‘*Maiti anayeishi*’ [lit. a living corpse], ‘*moto*’, [fire] and
299 ‘*Maiti inayo tembea*’ [lit. walking corpse]. These had a negative connotation on their day-to-
300 day life and their work as FSWs since it could cause them to lose clients.

301 HIV stigma did not only come from society, but also from close relatives and family
302 members. Participants provided various examples to explain the family reactions after finding
303 out that FSWs were using HIV medication:

304 *...she [FSW] started using the medicine [ARVs] immediately after she tested HIV-*
305 *positive ... but because she believed they [family] would support her, she told her*
306 *mother that she is using those [ARVs]. Instead of offering support, her mother called*
307 *her aunt [FSW’s aunt] to tell her that the girl brought bad luck in the family and that*
308 *she was a prostitute, and everyone who came home was told the same things [...] even*
309 *if it were you, would you accept to start the medicine? – PGD_16*

310 With multiple sources of stigma, participants discussed that some FSWs do not accept to go
311 to HIV care clinics located within their villages. A few discussed that some FSWs avoided
312 using transport offered by Sauti for clients to go to a nearby health facility to be linked to
313 care. They instead travelled to other places to get the medicines and use them secretly.

314 **Individual-level barriers**

315 *Perceived health status*

316 Low HIV risk perception plays a role in FSW's acceptance of linkage to care. Those who had
317 not developed symptoms of HIV considered themselves as being healthy, thus they did not
318 see the importance of linking to care even when they were told that they were infected.
319 Participants expressed that most FSWs who had taken HIV-test out of curiosity and found to
320 have HIV infection, denied the test results because they felt that they were in 'good physical
321 health'. In one FGD, a young woman stated that:

322 *"...You feel well just like everyone ... so you continue with your life" - PGD_16*

323 Contrary to popular expressions, however, a few participants felt that these sentiments were a
324 result of limited awareness on the mechanisms through which HIV progresses and the
325 importance of early initiation of care. For them, the HIV virus can stay in the human body for
326 several years while multiplying, and that manifestation of the symptoms are the final stages
327 that you are about to die.

328 *Fear of spoiling the relationship with partners or losing the clients*

329 Some participants reported that FSWs fear to link to care as this would alert their potential
330 clients and they would lose the clients. For those who had permanent partners feared to scare
331 them, this would lead to separation or break the relationships. With this fear, participants
332 reported that most FSWs found to be infected avoided to be linked to HIV care clinics
333 because their HIV status would be known.

334 **Discussion**

335 This study has documented context-barriers and facilitators for utilising HIV care and
336 treatment. We found that some Sauti Project intervention elements were critical in
337 influencing [motivators for] linkage to care. Consistent with other studies conducted in SSA,
338 use of peer-educators for reaching FSWs enabled a peer-to-peer sharing of knowledge about
339 prompt care and available alternatives for HIV services, which created a demand for both
340 project and health facility-based HIV clinical services (17). Besides, providing support
341 services through peer-escorted referral for individuals diagnosed with HIV promoted linkage
342 to care. As observed in other settings, our analysis shows that peer-escorted referrals
343 increased confidence and encouraged some FSWs to accept linkage to care (17). These
344 findings underscore the need for expanded coverage of peer-based prevention interventions
345 and comprehensive HIV services for FSWs (18-20). Shortcomings of a few peer educators
346 and home-based care providers in handling clients' information need to be addressed to
347 increase their acceptability in facilitating linkage to care.

348 Whilst participants also acknowledged the role of support services such as providing
349 transport fare and peer-support networks in promoting linkage to care, they discussed many
350 challenges that inhibit FSWs' linkage to HIV care at multiple levels, which merit future
351 interventions. At a system level, breach of confidentiality and disrespect from healthcare
352 providers; unfriendly service delivery environment; and the prolonged training sessions took
353 before enrolment care and treatment, perceived adverse effects of ARV hindered FSWs to
354 swiftly use care and treatment services. At a societal level, the stigma associated with
355 accessing HIV care and myths surrounding antiretroviral treatment, prevent FSWs from
356 accepting linkage to HIV care. At the individual level, we found that perceived health status
357 and fear of spoiling relationships with partners, negatively impede linkage to care. Although

358 more research is needed to address the broad range of barriers, these results highlight critical
359 entry points for interventions to improve linkage to HIV care and treatment among FSWs
360 diagnosed with HIV (21).

361 Participants described how fear of stigma and discrimination could act as a barrier to linkage
362 to HIV care or lead to delays in deciding to visit an HIV care and treatment facility after an
363 HIV diagnosis. FSWs often face multiple levels of stigma related to the social and structural
364 context of sex work (19, 22, 23) or as a result of household illness (24). Thus, it is not
365 surprising that stigma and discrimination continue and perhaps increasing among FSWs
366 living with HIV. In our study, FSWs highlighted that stigma and discrimination in the form
367 of verbal harassment and disclosure of HIV status within the healthcare setting were
368 significant barriers to their linkage to HIV care, which is likely because of their sex work
369 practices and HIV status combined. Interventions focused on health service providers to
370 reduce stigma and discrimination, such as sex work sensitisation training and participatory
371 dialogue, are urgently needed as they have the potential to increase linkage to HIV care
372 among FSWs, a finding that has been highlighted in other studies (20, 25). There is also a
373 need for community sensitisation that highlight the importance of support systems for people
374 living with HIV, to enhance acceptance of those who are diagnosed with HIV (26). It is
375 known that healthcare providers' stigma towards people living with HIV can be a reflection
376 of the broader negative social norms embedded in the community (27). Thus, addressing the
377 drivers of HIV stigma especially attitudes towards people living with HIV and a lack of
378 awareness on what constitutes stigma is critical to increasing linkages to HIV care. Studies
379 have shown that interventions which empower the community are useful and effective means
380 to increase tolerance and reducing HIV stigma (28). Therefore, it is crucial that community-
381 based HIV interventions such as Sauti include interventions aimed at increasing tolerance and
382 lessen HIV stigma at all levels.

383 Unfriendly service delivery 'environment' emerged as a leading barrier for FSWs to initiate
384 visits to HIV clinics. Although studies have shown that having a dedicated section for HIV
385 services at the facility level may increase the quality of care (29), this study found that FSWs
386 were concerned that such arrangement exposes them to other patients attending the facilities,
387 thus increasing individual stigma. In addition, while studies show that the length of adherence
388 sessions increases adherence to treatment in the general population (30), FSWs in this study
389 raise this as a concern and that it discourages them as it compromises their working time, and
390 that some health facilities opened only for eight hours a day. These findings point to the need
391 for communicating thorough information to FSWs on what to expect when they visit the
392 clinic, including whom they will see and when, and if possible the average time they should
393 expect to spend at the clinic for each visit and their rationale (31). Besides, scepticism
394 regarding the location of the clinic-space and the hours of operation shows the pervasive
395 nature of anticipated stigma, especially the expectation that when other people see them will
396 gossip, point fingers, or discriminate them (27). The findings further point to the potential for
397 initiation of pre-ART outreach services through FSWs' existing networks. It is possible to use
398 peer-educators to organise FSWs' in teams within their villages for pre-ART counselling
399 sessions and sample collection for confirmatory tests and other clinical procedures.
400 Community-based ART evaluations have shown that initiation of care through outreach
401 service has the most significant effect on the timely initiation of care, which leads to positive
402 health outcomes (32).

403 The myths and rumours about ARVs, coupled with a lack of correct information on HIV and
404 disease progression were barriers to linkage to HIV care. In this study, participants discussed
405 that the use of ARVs caused deterioration of the body and was the leading cause of the
406 observed sudden deaths in the community. These myths created fear among those who are
407 newly diagnosed with HIV infection and an increasing tension to those who are on treatment.

408 The continued myths and rumours about ARV points to the need of robust community
409 programme and a comprehensive communication plan, which will address how HIV stigma
410 plays out through multiple modalities as suggested in other studies (33). Such a programme
411 must ensure that there is a regular, open and consistent dialogue within the community, and at
412 all local government structures for a sustained information sharing. Local tailoring of
413 messages and materials may be the best approach for addressing the myths and rumours
414 preventing FSWs from linking to HIV care.

415 It is also important to provide more information regarding the health benefits of timely
416 initiation of ART to individuals diagnosed with HIV, and the preventive effect on the spread
417 of HIV to sexual partners when viral suppression has been achieved (34). Findings from this
418 study show that some FSWs fear linkage to care because their partners will know that they
419 are HIV-positive and are using ART, which can spoil their relationship. This suggests a lack
420 of understanding of the preventive benefits of early initiation of HIV treatment and the need
421 for partner involvement in HIV testing and counselling through index testing. Right
422 messaging to show that individuals who are virally suppressed not only are less likely to
423 develop HIV-related complications but also are less likely to pass on the virus to sexual
424 partners (35). Availing this knowledge to the community can reduce the enacted and
425 perceived stigma, which inhibits many people from disclosing their HIV status and seeking
426 appropriate care.

427 HIV risk perception, e.g. lack of HIV signs and symptoms consistently emerged as a barrier
428 to linkage to care. This finding suggests limits in community awareness of HIV progression
429 and the importance of early initiation of ART. Such knowledge is urgently needed if
430 programs are to increase FSWs accepting to be initiated to HIV care. Results in this study
431 also found that FSWs are more likely to trust their peers and rely on their informal networks
432 to provide them with information on available health services. Since FSWs are hard to reach,

433 it could be a challenge for healthcare providers to reach and deliver the needed health
434 information necessary to change the risk perceptions hindering linkage to care. However,
435 studies have shown that in contexts where sex work is illegal, most FSWs engage in some
436 business that helps to guise their identities. Such business includes being a bar attendant,
437 working in massage pallor, food selling spaces, saloon and so on (36, 37). Reaching workers
438 in these places with health information, and recruiting peers who would reach FSWs will
439 increase the reach of health literacy on the importance of prompt HIV care, which will have
440 the potential to increase linkage to care. The results from previous studies on the
441 effectiveness of peer education programs for FSWs showed that peer education intervention
442 significantly increased knowledge on HIV (38), reduced STIs, and increased condom use
443 among FSWs (39). Thus, interventionists and health professionals may achieve the goal of
444 increasing linkage to care by working closely with peer educators.

445 Other studies conducted in SSA have also underscored how transport related costs could
446 hinder linkage to care (40-42). Consistent with those studies, our study underscores the need
447 to pay attention to salient issues such as logistical constraints that can negatively influence
448 FSWs decision on linkage to HIV care.

449 **Study limitations**

450 As study participants were limited to FSWs who received services provided by Sauti Project,
451 the information may not describe barriers and facilitators to linkage to HIV care for FSWs in
452 non-Sauti implementation areas. Readers ought to be cautious that participants in this study
453 were not selected based on HIV status, it is likely that some of the information shared is
454 based on perceptions and not lived experiences. Future studies may want to interview FSW
455 stratified into groups based on HIV status if this is feasible and can be done in a non-harmful
456 way.

457 **CONCLUSION**

458 Linking HIV-positive FSWs to care is complex and involves a range of barriers at the system,
459 societal and individual levels. Although the socio-ecological perspective provides an
460 approach for understanding how these multi-level factors interact to influence linkage to care,
461 this study underscores the need for understanding the salient factors for program
462 prioritisation. In addition, health services and future interventions should consider the salient
463 facilitators and barriers identified in this study to improve linkage to care among FSWs in
464 similar contexts.

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