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Exploring Treatment Needs and Expectations for People Living with HIV in South Africa: A Qualitative Study

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Abstract

The UNAIDS 90-90-90 treatment targets aim to dramatically increase the number of people who initiate antiretroviral therapy (ART) by 2020. Greater understanding of barriers to ART initiation in high prevalence countries like South Africa is critical. Qualitative semi-structured interviews were conducted with 30 participants in Gugulethu Township, South Africa, including 10 healthcare providers and 20 people living with HIV (PLWH) who did not initiate ART. Interviews explored barriers to ART initiation and acceptability of theory-based intervention strategies to optimize ART initiation. An inductive content analytic approach was applied to the data. Consistent with the Theory of Triadic Influence, barriers to ART initiation were identified at the individual, social, and structural levels. Results suggested high acceptability for intervention strategies involving trained HIV-positive peers among South African PLWH and healthcare providers. Research is needed to evaluate their feasibility and efficacy in high HIV prevalence countries.

Compliance with Ethical Standards:

Conflict of Interest: The authors declare no conflicts of interest.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

Keywords

HIV; antiretroviral therapy; qualitative; South Africa

INTRODUCTION

The UNAIDS 90-90-90 treatment targets aim to dramatically increase the number of people who initiate antiretroviral therapy (ART) and achieve viral suppression by 2020 (1). ART initiation is a key step in achieving viral suppression, which is critical to preventing transmission of the virus and extending the longevity of people living with HIV (PLWH) (2–5). Yet, reaching the UNAIDS targets will be challenging in high HIV prevalence countries like South Africa where approximately half of the seven million PLWH are not yet accessing ART despite universal eligibility (6).

Barriers to ART initiation may exist at the individual, social, and structural levels (7). The Theory of Triadic Influence integrates constructs from previous theories of health behavior change (e.g., Health Beliefs Model, Theory of Planned Behavior, Social Learning Theory), and posits that factors at each of these levels independently and interactively affect decisions to engage or not engage in health behaviors (7). Individual-level factors may include intrapersonal obstacles, such as negative emotions, problems coping, or lack of motivation. Social-level factors may include interpersonal concerns, such as enacted and anticipated stigma (8, 9). Structural-level factors may include obstacles in the environment, such as distance to an HIV clinic. The Theory of Triadic Influence has primarily been applied to understanding substance use and misuse, particularly among adolescents and young adults, but can be applied to a wide range of health behaviors including those related to HIV (7, 10). Although previous work has begun to examine barriers to ART among PLWH in South Africa (11–13), research to date has yet to apply the Theory of Triadic Influence as an analytic lens to identify barriers in a comprehensive way across multiple levels of influence.

The Theory of Triadic Influence further suggests that interventions should address barriers at each of the individual, social, and structural levels to effectively improve health behaviors (7). Moreover, previous research and theory suggests that people who have tested positive for HIV, but have not initiated care, may benefit from intervention strategies involving assistance from peers living with HIV (14–25). At the individual level, use of autonomy supportive strategies like open questions and reflective listening can be used by peers to create an empathic, collaborative, non-confrontational style of communication which may lead to behavior change by enhancing PLWH's intrinsic motivation and confidence (14–19). At the social level, social support from peers including comfort, assistance, and/or information from others may enhance PLWH's resilience to interpersonal stressors like stigma (20). At the structural level, patient navigation from peers may improve engagement in care by helping PLWH identify and overcome barriers to health services (21–23). Early evidence supports the use of peer support specifically to improve ART initiation (24, 25). Nevertheless, the extent to which these more comprehensive intervention strategies delivered by HIV-positive peers would be acceptable to South African healthcare providers and PLWH is unknown.

In the current study, we used the Theory of Triadic Influence to explore barriers to ART initiation in South Africa at the individual, social, and structural levels reported by healthcare providers and PLWH who had not initiated ART. Based on previous research and theory (14–23), the team hypothesized that intervention strategies including motivational interviewing techniques, social support, and patient navigation delivered by HIV-positive peers may address a variety of barriers to ART initiation at each of the levels defined by the Theory of Triadic Influence. We therefore also examined the extent to which intervention strategies involving peers were acceptable to healthcare providers and PLWH.

METHODS

Participants and procedures

Qualitative semi-structured interviews were conducted with 30 participants, including 20 PLWH and 10 healthcare providers, in Gugulethu Township, South Africa in 2015. Gugulethu has a population of roughly 400,000 people. Forty-eight percent of residents are unemployed and 64% live on <400 SA Rand (ZAR) [approximately <US\$40] per month. The vast majority of the population uses local public sector health services that are provided free of charge. In 2013, the HIV prevalence among women attending local antenatal care services was 21.7% (26). Within Gugulethu, we recruited participants who had been previously tested for HIV at the main public health sector testing facility (GCHC), broadly representative of the spectrum of free standing HIV testing services across South Africa. This site has been previously well characterized (27, 28), and has provided treatment for free since September, 2002.

PLWH were recruited from a sample of 500 ART-eligible PLWH participating in a longitudinal quantitative study of HIV treatment refusal. Study eligibility criteria for PLWH in this qualitative study included: (1) adults (>18 years old) living with HIV who had not initiated ART within 3 months of learning eligibility, (2) ART naïve, (3) lived within 60 kilometers of clinic, (4) English or isiXhosa speaking, and (5) eligible for ART under South African guidelines. Medical records were screened by study staff and eligible individuals were invited by study staff to participate in the study. Healthcare providers included counselors and nurses at the HIV testing center, as well as treatment staff and adherence counselors running community-based adherence clubs, which provide expanded access to treatment and support for stable PLWH who are in care (29). Study staff also invited healthcare providers to participate. All individuals who were approached about the study agreed to participate. Participants provided written informed consent. Data collection was approved by the Research Ethics Committee of the University of Cape Town and Partners Institutional Review Boards.

A research assistant performed in-person interviews in English or isiXhosa at a secure, centrally-located field office. Interviews followed a semi-structured protocol designed to explore the needs of PLWH associated with ART initiation and acceptability of intervention strategies including peer support and peer navigation from HIV-positive peers to optimize ART initiation. As shown in Table I, which includes examples of questions for PLWH and providers, most questions were asked of both PLWH and providers with several questions being tailored for PLWH or providers specifically. Scenarios were presented as a technique

to extract more specific information about barriers to care. Scenarios described an individual who tested positive for HIV and was in the process of deciding whether to initiate HIV treatment. Participants were asked whether the individual would start treatment and why. Interviews lasted 30–45 minutes and were digitally recorded, transcribed, and translated into English if conducted in isiXhosa. Participants received 100 South African Rand (the equivalent of US\$10).

Analysis

An inductive content analytic approach was applied to the data. Coding began with a provisional “start list” of codes based on the Theory of Triadic Influence and prior research (7, 11, 30). These included barriers to care at the individual level (i.e., internalized stigma, self-assessed health, self-efficacy, knowledge, coping), social level (i.e., disclosure, enacted and anticipated stigma, social support), and structural level (i.e., access to care, quality of care). Two members of the research team with training in qualitative research methods independently read 20% of the interviews, applied codes from the “start list,” and generated new codes based on identified themes not represented on the “start list.” They then developed a codebook incorporating codes from the “start list” and the new codes. Codes were grouped into four clusters representing barriers to care at the individual, social, and structural levels, and acceptability of intervention strategies. The team members then coded an additional 20% of the interviews using the codebook. They had strong interrater reliability (Cohen’s kappas = 0.81 for individual-level barriers, 0.92 for social-level barriers, 1.0 for structural-level barriers, and 0.85 for intervention reactions). One team member then coded the remaining interviews. All coding was conducted in Dedoose 7.5 (31). After the codes were applied, members of the research team examined the distribution of themes, compared quotes of PLWH and providers, and identified illustrative quotes.

RESULTS

Participant characteristics

Participant characteristics are described in Table II.

Barriers to care

Reflecting the Theory of Triadic Influence, participants described multi-leveled barriers to care (see Table III). Both PLWH and providers highlighted barriers at the individual, social, and structural levels.

Individual level—At the individual level, participants primarily focused on barriers to initiating ART relating to emotions, coping, and motivation. PLWH and providers discussed *emotions*, or affective states, that made it difficult to initiate ART. Participants emphasized that people experience a range of powerful, often negative emotions when first diagnosed with HIV. PLWH described feelings of disbelief and shock that they had tested HIV positive, including one individual who noted that she believed that she couldn’t “become HIV positive... I was shocked when I was told, when I had blood drawn, that I am HIV positive.” Providers also observed shock among individuals who were newly diagnosed (Table III, Quote 2). PLWH described feeling fear when they had learned of their status, including fear

for their lives, of how ART would affect them, and how others would react to them. One PLWH noted that PLWH are “afraid that he/she could die any moment now,” and another noted that PLWH are “scared of the treatment itself.” A PLWH highlighted distress and anger as barriers to treatment when prompted by the scenario (Table III, Quote 1). PLWH also identified their emotional reactions to their own diagnosis as a barrier for them, with one noting that they did not initiate treatment because they still “needed to process everything.”

Participants described challenges *coping* with HIV diagnoses, which prevent PLWH from initiating ART. Providers observed that some people do not immediately accept their diagnosis (Table III, Quote 4). PLWH described other PLWH who coped with their diagnosis with substance use. One described a friend who had been diagnosed with HIV but was not engaged in treatment: “every time we’re hang(ing) out... she’s drinking and keeps on saying, ‘I am sick.’ It means that you have not accepted it yet.” Others engaged in passive religious coping and believed that God would heal them (Table III, Quote 3). In response to the scenario, several participants encouraged acceptance and active coping among recently diagnosed PLWH. One PLWH recommended that “another solution is for (the protagonist of the scenario) to tell himself that he is ‘HIV positive, and I’m going to attend treatment.’”

Participants highlighted lack of *motivation* as a reason for not initiating ART. Providers perceived some PLWH to be unmotivated, describing them as “lazy” (Table III, Quote 6). Another provider felt that motivation was a more prominent barrier to treatment initiation than knowledge, given that information about HIV was readily available in the community. They stated that “the radio and TV are already talking about this [HIV]. But the people are just stubborn.” Providers’ perceptions were based, in part, on their past experiences with trying to engage PLWH in care. One noted that the providers at their clinic had tried “many programs in Gugulethu but support was very poor” because people “only want to go when they will get something” such as free handouts. PLWH also described laziness as a barrier to treatment (Table III, Quote 5). Both providers and PLWH noted that motivation was important for engagement in care, and that motivated PLWH would be more likely to initiate and remain adherent to care. Participants identified health, children, and incentives as motivating factors for treatment initiation. One provider noted that “living a long life” and “living for the sake of your kids” would motivate PLWH to initiate ART.

Other barriers at the individual level that were mentioned less frequently included self-assessed health, competing needs, and internalized stigma. Specifically, individuals who perceived themselves to be healthy, had competing demands such as work, or who felt internalized HIV stigma were less likely to initiate ART. Providers and PLWH noted lack of knowledge as a barrier, including having access to accurate information about one’s own health (e.g., viral load, CD4 count). Providers highlighted acceptance as key, with one stating that “in healing oneself, the only way to take your medication is through accepting yourself.”

Social level—At the social, or interpersonal, level, participants described anticipated and enacted stigma, lack of disclosure and concealment, and treatment from healthcare providers as barriers to initiating ART. Participants noted that *stigma* from other people, including

expectations of stigma in the future and experiences of stigma in the past, prevented PLWH from accessing HIV treatment. Gossip from community members and neighbors was frequently discussed. One provider noted that PLWH don't want to start treatment because "there are many people who will talk about him," and a PLWH said that PLWH are "afraid of being made fun of by people, because people are saying things about people who are HIV [positive] and they forget that people who have HIV people are just like other people." Gossip included calling PLWH names, like "a slut," as described by a provider and judging them to be "an immoral person," as described by a PLWH. Participants described rejection from family members, including a provider who noted that "they aren't accepting... the parents or the sisters or the brothers." A heightened risk of violence was also described, particularly for women whose male partners became aware of their HIV status (Table III, Quote 8). Participants noted that PLWH feared losing their job if their employer found out about their HIV status. Anticipated stigma, or worry about being treated differently, kept PLWH from accessing care at the HIV clinic (Table III, Quote 7).

Accessing treatment at the HIV clinic was described as involving a significant risk of unintended *disclosure* of one's HIV status to other people, which placed PLWH at risk of stigma. PLWH therefore avoided treatment, including going to the HIV clinic and taking ART, to *conceal* their HIV status. PLWH who were concealing their HIV described fear that others would gossip about them, possibly telling their families and romantic partners, and therefore did not initiate treatment at the clinic (Table III, Quote 9). One provider noted that "it's a small village and... if you go to that clinic, you go to that door, you have disclosed already. Immediately you go to that building, it's a disclosure." Some PLWH feared that the nurses would gossip about them, including one who said that PLWH worry that others "are talking [about them], including the nurses themselves." Accessing medication at the pharmacy also carried risk of disclosure, given that PLWH could be identified by medical charts that looked different from the charts of patients not living with HIV (Table III, Quote 10).

Participants described poor *treatment from healthcare providers* as a barrier to care. Several providers described harsh interactions between healthcare providers and PLWH (Table III, Quote 12). One provider described "the attitude" of providers as a problem and noted that "there are some people who still don't have ways to speak to the patient, they shout to the patient." One provider described their own experience when another provider insisted that they test for HIV before they were ready: "I said I don't want to test HIV. And I had a struggle with that doctor... I could see this doctor is fighting with me now because he's calling everyone... showing me... look 'This lady doesn't want to go to room 28. Maybe she already knows. Go and check *her* history.' So, I was offended... that made me so furious." Participants also discussed poor treatment from other staff members at the clinic. One provider noted that people do not initiate treatment because of "the reception... you'll feel like going out again because there is no welcoming... And sometimes you are traumatized, you've just heard that you are HIV positive... And then comes this face in this place, stern and telling you what to do or not to do." PLWH who did not immediately initiate care after their diagnosis anticipated that they would be scolded or reprimanded, and so avoided the clinic (Table III, Quote 11).

Structural level—At the structural level, participants primarily identified issues related to *accessing care*. They discussed long waiting lines to see the doctor (Table III, Quote 14) and at the pharmacy. They also noted that PLWH may underestimate how much time it will take for their check-up, with one provider stating that “they don’t know the clinic’s procedure... the procedure to take blood and all that.” Both providers and PLWH noted that PLWH have other responsibilities, including work, that prevent them from going to the clinic (Table III, Quotes 13–14). Some participants noted that PLWH cannot afford transportation to the clinic (Table III, Quote 13). One PLWH described safety concerns, stating that “you get robbed here outside on the road” while going to and from clinic.

Acceptability of intervention strategies

Participants described their general reactions to the intervention strategies, as well as their thoughts on who HIV-positive peers should be, what interventions should do, and where interventions should take place (see Table IV).

General reactions—Participants were generally supportive of the proposed intervention strategies, which they felt could help overcome barriers to ART initiation. Both PLWH and providers approved of peer support. PLWH noted that support from peers would motivate PLWH to access treatment and help them cope with their diagnosis (Table IV, Quote 1). Providers thought that peers might be able to motivate PLWH to access treatment and provide reminders of appointment times. Yet, providers also worried that peer support would prevent PLWH from taking responsibility for their health (Table IV, Quote 2).

PLWH and providers both noted that interventions should be tailored to individual needs, or patient-centered. They emphasized that not everyone needs peer support, with one provider stating that “it depends on that person’s situation and so on.” Participants noted that intervention strategies will not be effective if they do not address the unique barriers to care experienced by individual PLWH. One PLWH said “if a person doesn’t want the medication, ... even if you can take it to him/her, if he/she won’t take it, he/she won’t take it... it’s not effective if he/she doesn’t want it.”

HIV-positive peers—Participants generally agreed that PLWH who were doing well on ART could support others’ treatment engagement, showing that it is possible to have a good quality of life while living with HIV (Table IV, Quotes 3–4). PLWH noted that they would feel less shame talking to someone who also lived with HIV. Participants noted that peers would be better suited to help PLWH overcome barriers to care based on their own experiences, including how they cope with stigma. Participants described qualities of good peers, including having lived with HIV for a long time, being adherent to ART and attending clinic visits, and being healthy. One participant recommended matching peers on characteristics such as age and gender.

There was some disagreement regarding whether family and friends would be good peers. Some participants noted that family members who lived with patients could encourage them to take their medication, with one PLWH saying “It should be his/her sister who keeps pushing him/her, that, ‘Hey, dude, it’s time to take your treatment’ ... It’s necessary to have someone even at home, who has the responsibility to say ‘Let’s go, dude, to have you

checked for something.” Several participants argued that friends would not be ideal HIV-positive peers, with one provider noting “your friend doesn’t give a damn whether you are taking your medication or not.” PLWH who had not disclosed their HIV status said that they would prefer not to have a family member or friend as a HIV-positive peer to protect their privacy.

Intervention content—Participants recommended several strategies to address barriers to care. Participants identified ways in which HIV-positive peers could provide multiple forms of social support to address individual- and social-level barriers to care. To address barriers related to emotions, avoidant coping, and enacted and anticipated stigma, participants suggested that HIV-positive peers help patients develop positive coping strategies such as talking with other people. PLWH felt that peers could act as role models by sharing their stories and showing PLWH that other people successfully live with HIV (Table IV, Quote 5). Providers also felt that HIV-positive peers could enhance their motivation to engage in care including by encouraging them to take their medication and go to the clinic (Table IV, Quote 6). Participants recommended that HIV-positive peers remind PLWH of their appointments and times to take medication, as well as help PLWH troubleshoot structural care access issues (e.g., transportation). Providers emphasized that HIV-positive peers must be prepared to address broader issues that may affect HIV care, including food insecurity, employment, and housing. One noted, “when you go to someone that is HIV positive they will tell you... ‘we don’t have food, we don’t have money.’ They must be expecting that and they must be able to tell them about the support groups, about SASSA [South Africa Social Security Agency], the social grants, about everything that can help them.”

Intervention location—Participants generally suggested integrating intervention strategies into community settings. PLWH emphasized that providing counseling in the community could help overcome barriers among participants who are unmotivated to come to clinic (Table IV, Quote 7) and stigma anticipated when visiting clinics. Providers noted that integrating interventions into the community could help overcome barriers related to structural care access (Table IV, Quote 8). Participants suggested that HIV-positive peers should be inconspicuous so that community members cannot tell that they are affiliated with the HIV clinic.

DISCUSSION

In this qualitative study of PLWH and healthcare providers, we found barriers to ART initiation at the individual, social, and structural levels, as well as evidence for the acceptability of intervention strategies to address these barriers. Barriers primarily included emotions, coping, and motivation at the individual level; anticipated and enacted stigma, disclosure and concealment, and treatment from healthcare providers at the interpersonal level; and access to care at the structural level. PLWH and providers generally reported similar barriers, with some differences regarding which barriers were emphasized by the two groups of participants. PLWH placed a greater emphasis than providers on emotions and challenges with coping as barriers, whereas providers placed a greater emphasis than PLWH on lack of motivation and poor treatment from providers as barriers. Some providers’ emphasis on lack of motivation as a barrier to ART initiation may reflect the fundamental

attribution error, wherein individuals tend to over-emphasize the role of internal, personality characteristics (including personality flaws) and under-emphasize the role of external, structural characteristics in guiding others' behavior (32).

Our findings both replicate and extend past work on barriers to ART initiation in South Africa. Replicating past work, we found that issues related to stigma, disclosure, and care access act as barriers to ART initiation (11–13). In contrast to some past work (12), we found that providers agreed with PLWH regarding the significance of structural-level barriers such as long lines at the clinic and transportation. Several of these factors have also been identified as barriers to care among newly diagnosed PLWH specifically, including stigma and accessibility of clinics (33). Extending past work, we were able to differentiate between barriers at the individual, social, and structural levels by applying the Theory of Triadic Influence to our analyses. This more nuanced understanding of barriers can contribute to intervention efforts to improve ART initiation in South Africa.

PLWH and healthcare providers who participated in this study generally found the proposed intervention strategies to be acceptable and thought that these strategies may lead to greater ART initiation. Proposed intervention strategies led by HIV-positive peers included addressing individual, social, and structural level barriers to ART initiation by using autonomy supportive strategies like open questions and reflective listening to enhance intrinsic motivation and confidence to make necessary changes while providing social support and peer navigation. Past qualitative work in Tanzania suggested that PLWH are reluctant to identify a “treatment buddy,” or member of their own social network who would support their ART adherence (34). Participants of this study also expressed ambivalence regarding choosing a family member or friend to act as a HIV-positive peer; however, they generally responded positively to the idea of PLWH who were engaged in care as HIV-positive peers. Participants perceived that HIV-positive peers could address individual-level barriers to ART initiation by role modeling positive strategies to cope with emotional reactions to HIV and motivating PLWH to engage in care. They also perceived that HIV-positive peers could address social-level barriers by providing social support to PLWH experiencing stigma and teaching PLWH disclosure skills. Providers emphasized that HIV-positive peers would need training in HIV, including up-to-date information about research on HIV and HIV treatment, as well as more general social and life skills. Some providers also expressed concern that the intervention strategies would prevent PLWH from taking responsibility for their health, whereas PLWH did not note these concerns. Both PLWH and providers emphasized that intervention efforts should be integrated into community settings.

This study examined barriers to ART initiation and acceptability of theory-based intervention strategies to address these barriers in Gugulethu Township, South Africa. Research is needed to enhance ART initiation in South Africa, where over half of PLWH are not currently accessing ART. Yet, findings may not generalize beyond Gugulethu Township to other areas of South Africa or the world. More work is needed to examine barriers to ART initiation and acceptability of intervention strategies in other socio-cultural contexts. Moreover, quantitative studies could build on this qualitative work by examining statistical associations between the barriers identified in this study and actual ART initiation, and an

intervention study is needed to determine whether these intervention strategies would improve ART initiation.

CONCLUSIONS

Theory-driven socio-behavioral interventions that address the multi-level barriers to ART initiation are critical to meeting the unique needs of PLWH who have not initiated ART. The current study suggests that such comprehensive interventions involving peers living with HIV are acceptable to South African PLWH and healthcare providers. Peers may address individual level barriers to ART initiation such as emotions, coping, and motivation through the use of autonomy supportive strategies like open questions and reflective listening; social level barriers such as enacted and anticipated stigma, disclosure and concealment, and treatment from healthcare providers through social support; and structural level barriers such as access to care through patient navigation. Peers may also play a role in adapting intervention strategies to the individual needs of PLWH. Future studies should assess feasibility and efficacy of these more comprehensive interventions in low-resource settings.

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Table 1

Example questions from qualitative protocols on barriers to care and acceptability of intervention strategies for PLWHA and healthcare providers

Question Topic	PLWHA Interviewee	Healthcare Provider Interviewee
Barriers to ART Initiation	1. In general, what do you think are the major issues facing newly diagnosed people with HIV?	2. What kinds of things can make it easy or hard for people to get started on treatment? What are the major barriers related to getting care for HIV?
Feedback on Potential Intervention Strategies	3. What kinds of programs do you think would be useful for helping newly-diagnosed people to start treatment? 4. Sometimes HIV+ people don't get into care. What do you think about using peers to help support people who have not engaged in care? What could peers do to help patients who don't want to start ART? In what ways might peers be more or less helpful than other types of supporters? 5. We were thinking that peers could accompany patients to appointments and help them to start treatment. We would like to hear what you think of this? Do you see any practical issues that we should be thinking about? 6. We are also considering training peers to help motivate individuals to engage in care. What areas do you think we need to cover in this training? How do you think peers could best motivate individuals to engage in care?	
Feedback on Scenarios	Finally, I would like to get your feedback on different kinds of scenarios that people may face when getting HIV care in South Africa. Specifically, we will now read you a story about a person living with HIV trying to decide if they will start treatment. We are hoping to get your impression on whether or not you think this person would start medication and why. Thandekile told a story about what brought her in to get tested and how she felt about the results: "I live in a rural area. I came in because I had an encounter with my boyfriend and I thought I should get tested, since I think he may be having other girlfriends. I found out I was HIV positive and was so upset. This is a small place, even though you trust the nurses and stuff like that. People who are in the clinic, they know that you go to that door when you are HIV positive, and you get called a "tracker". You come in this way, so they will notice, "Wow, she is also HIV positive." So they will start talking, I have got my ex-boyfriends in this area. I have been told I qualify for treatment, and I am just not sure what to do next." 7. What do you think Thandekile will do? Will he/she start treatment? Why or why not?	

Table II

Socio-demographic characteristics of participants

Characteristic	% (n) or M (SD)
Participant type	
Person living with HIV	66.7 (20)
Healthcare provider	33.3 (10)
Gender	
Woman	76.7 (23)
Man	23.3 (7)
Age	37.45 (8.48)
Ethnicity	
Xhosa	83.3 (25)
Zulu	10.0 (3)
Sesotho	6.7 (2)
Relationship status	
Single	70.0 (21)
Cohabiting	16.7 (5)
Married	10.0 (3)
Widow	3.3 (1)
Children	
Yes	83.3 (25)
No	16.7 (5)
Employment status	
Employed	66.7 (20)
Self-employed	10.0 (3)
Unemployed	23.3 (7)
Residence	
House	46.7 (14)
Shack	43.3 (13)
Backroom	10.0 (3)

Table III

Participant quotes representing multi-level barriers to care

Barrier	PLWH	Providers
Individual Level		
Emotions	1. "I doubt that he is going to get started because I hear him saying that he is upset... it's this anger that is going to make him unable to go to the clinic."	2. "Because of the shock, since the person has just come to learn (something new about) himself."
Coping	3. "It's God who decided I should have HIV. It's him again who can decide how I live my life... I will never start taking ARVs. I don't even eat anything to boost my body."	4. "It's a process... going through the denial process. You won't accept, no?"
Motivation	5. "There are other people who are lazy to go to the clinics. The person ends up saying 'Oh no, I will go tomorrow.' ... Again, tomorrow comes, again he/she doesn't go."	6. "They are lazy to come to clinic every time. They will ask, 'Go (on my behalf)... Can you please fetch my tablets?' They will ask for favors and favors and favors."
Social Level		
Anticipated and enacted stigma	7. "If it becomes known in the township that you are HIV positive, like, people don't treat you as if you are like them. They treat you differently... That's the reason you wish you wouldn't be seen when entering this building."	8. "I don't think she is gonna start medication because she is scared. The moment you come to the clinic to take your medication, they gonna tell other people 'oh I saw so and so in the clinic' and then they will go to your exes and then your exes can kill you because you know the rural areas there is not much information about HIV. She is not safe."
Disclosure and concealment	9. "The reason I hadn't started was because I was afraid because I hadn't disclosed at home. I hadn't disclosed to anyone, not even my boyfriend. So, now I also feared going into a public space, among people I know, who will be talking about me at the clinic. So, those are the things that made me afraid to get started."	10. "Our patients, they run away because of that plastic covers... when they went to the pharmacy, the people, even her neighbor sitting there, can see that this one came from (the HIV clinic)... The people they know at the pharmacy, 'this one is HIV-positive,' they saw the folders."
Treatment from healthcare providers	11. "Well, other people tend to really not want (anything to do with) the clinic. That's the problem... he/she is afraid that he/she will be reprimanded here at the clinic, that he/she will be asked 'why are you staying away?' ... People say, 'the nurses at the clinic reprimand/scold at you and so on.' You see?"	12. "Even the doctors! The doctors, they don't have way to talk to the patients. She did not even ask, 'are you still staying in this address?' Just take the paper and say, 'not belonging to this clinic.' ... Especially the newly diagnosed patients. They still have that anger, that denial, so they need that."
Structural Level		
Access to care	13. "Others are working during the week. And others don't have money, perhaps they are far away from the clinics. They do not have transport fare to come to the clinic."	14. "Waiting queues. Long queues, they wait for the long day! ... They want to go to work. They don't have time to go to the clinic because they are working."

Table IV

Participant quotes representing reactions to the proposed intervention strategies

	PLWH	Providers
General reactions	1. “Yes, sisi. I think it’s a good idea... She can see that she has some support, so she stays positive all the time, and the (thought) that ‘I am now HIV positive’ is steadily leaving the mind. She sees herself, she (can) see herself that she’s a normal person.”	2. “I am a bit skeptical about that kind of a support because ... people won’t take full responsibility of their lives. They will tend to lean on the system because they expect that this is what the system needs to give them.”
Treatment partners	3. “Like, if you’re being supported by someone who’s got what you’ve got... Even if your soul (is) aggrieved, you know, you do realize that, ‘Wow, well this person is nevertheless telling me, he/she is nicely explaining to me, he/she has never defaulted, he/she is taking the treatment properly. So, it’s best if I also do what do what this person is doing. (So that) I can also live a long life. Because if I am (now) being supported by you, the person who already got this, I can also become well and have good company because you are also HIV positive.’”	4. “Once they are told they are HIV positive they think about death. I thinking that we need a program that will involve them in many ways and involve the people who’ve been HIV (positive) for years successfully, more than 20 years. I think they need to see (it for themselves). Rather than (merely) telling them: ‘there are people who’ve lived with HIV for twenty years.’ They need to see those people.”
Intervention content	5. “Like talking, chatting with me, the one who hasn’t started. Like, a person explains to you about his/her own situation so that you can also know that this thing that we have around is treatable, that you’re not the only one who has it, you see?”	6. “Your peers are the ones who motivate you, ‘don’t forget to take your medication, please go to your clinic because it’s your appointment date, and do you still remember what the doctor told you that you were sick or whatever.’ So they are playing a very big role.”
Intervention location	7. “He/she should get a visit and receive support there. I think people like that are the ones you need to visit in their homes, perhaps sit him/her down and talk to him/her. Show him/her (the way).”	8. “Let’s just close these long queues and go close to the people.”