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Barriers to Care among People Living with HIV in South Africa: Contrasts between Patient and Healthcare Provider Perspectives

Laura M. Bogart[1], **Senica Chetty**[2], **Janet Giddy**[2], **Alexis Sypek**[3], **Laurel Sticklor**[4], **Rochelle P. Walensky**[3,5,6], **Elena Losina**[7], **Jeffrey N. Katz**[8], and **Ingrid V. Bassett**[3,5]

[1]Division of General Pediatrics, Boston Children's Hospital; and Department of Pediatrics, Harvard Medical School, Boston, MA

[2]McCord Hospital, Durban, South Africa

[3]Division of General Medicine, Massachusetts General Hospital, Boston, MA

[4]Division of General Pediatrics, Boston Children's Hospital, Boston, MA

[5]Divisions of Infectious Disease, Department of Medicine, Massachusetts General Hospital; and Department of Medicine, Harvard Medical School, Boston, MA

[6]Division of Infectious Disease, Department of Medicine, Brigham and Women's Hospital

[7]Department of Orthopedic Surgery, Brigham and Women's Hospital; Harvard Medical School, Boston, MA; and Department of Biostatistics Boston University School of Public Health

[8]Division of Rheumatology, Immunology and Allergy and Department of Orthopedic Surgery, Brigham and Women's Hospital; and Departments of Medicine and Orthopedic Surgery, Harvard Medical School, Boston, MA

Abstract

We collected qualitative data (semi-structured interviews with 11 healthcare providers and 10 patients; 8 focus groups with 41 patients) to identify barriers to linkage to care among people living with HIV in South Africa who were not yet taking antiretroviral treatment. Patients and providers identified HIV stigma as a sizable barrier. Patients felt that stigma-related issues were largely beyond their control, fearing discrimination if they disclosed to employers or were seen visiting clinics in their community. Providers believed that patients should take responsibility for overcoming internal stigma and disclosing serostatus. Patients had considerable concerns about inconvenient clinic hours, long queues, difficulty in appointment scheduling, and disrespect from staff. Providers seemed to minimize the effects of such barriers and not recognize the extent of patient dissatisfaction. Better communication and understanding between patients and providers is needed to facilitate greater patient satisfaction and retention in HIV care.

Keywords

Linkage to Care; HIV/AIDS; Qualitative Methods; South Africa; Stigma

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Corresponding Author: Laura M. Bogart, PhD, Division of General Pediatrics, Boston Children's Hospital Boston, 300 Longwood Avenue, Boston, MA 02115. Phone: (857) 218-4073; laura.bogart@childrens.harvard.edu.

Introduction

In South Africa, 5.6 million people, approximately 11% of the population, are living with HIV (UNAIDS, 2011). However, as of 2010, only 1.4 million people in South Africa were receiving antiretroviral treatment (ART) (WHO, 2011), and half of newly-diagnosed patients fail to obtain CD4 count test results promptly after diagnosis (Losina et al., 2010) – the first step in initiating care. Most deaths occur before patients start ART (Fairall et al., 2008).

Improving access to care soon after diagnosis would greatly improve survival (Lawn, Harries, Anglaret, Myer, & Wood, 2008). However, little is known about losses to follow-up that occur after diagnosis but prior to ART initiation. Socio-demographic factors such as poverty, lack of insurance, and rural area residence are barriers to accessing care in South Africa (Harris et al., 2011; Nachega et al., 2006). Patients also may need to travel far to reach clinics, which often requires taking time off from work and paying for transportation (Coetzee, Kagee, & Vermeulen, 2011; Tanser, Gijsbertsen, & Herbst, 2006). Psychosocial factors such as high HIV stigma, which is intertwined with issues of lack of serostatus disclosure and poor social support, as well as HIV-related misconceptions, also contribute to low treatment initiation and care utilization (Bassett et al., 2010; Coetzee, et al., 2011; Finnie et al., 2010; Mitchell, Kelly, Potgieter, & Moon, 2009; Nachega, et al., 2006). For example, stigma, may prevent patients from confiding in others, leading to a lack of support for emotional and tangible needs (e.g., transport to clinic), as well as a reluctance to take medications in front of others. Across chronic conditions, patients in South Africa also report negative perceptions of care due to long wait-times, understaffing, and poor patient-provider relationships (Goudge, Gilson, Russell, Gumede, & Mills, 2009; Selman et al., 2009). Most prior research has focused on care utilization barriers in general, rather than those specific to the critical period between HIV diagnosis and care initiation. Furthermore, little research has examined healthcare provider perspectives; because providers treat many patients over time, they may have insights about system-wide challenges that would be missed by patients.

We used qualitative techniques to identify barriers to linkage to care among people with HIV who had not yet initiated ART. We elicited feedback from people with HIV and medical and social service providers, and compared and contrasted perspectives using patient and provider semi-structured interviews, and patient focus groups. Both focus groups and interviews were used to capture a range of themes from the interviews (especially on reasons for delaying care) and deep insights from dynamic focus group discussions (Seal, Bogart, & Ehrhardt, 1998).

Methods

Setting

This study was conducted from January-March, 2010 at McCord Hospital in Durban, KwaZulu-Natal, the South African province with the highest HIV prevalence (UNAIDS, 2009). McCord is an urban, state-aided, semi-private medical center that predominantly serves African-Zulus. From March-November 2007, the prevalence of HIV among people tested in the McCord Hospital outpatient HIV testing program was 48% (Bassett et al., 2011). An HIV clinic is located in an adjacent building on the hospital campus.

Eligibility and Recruitment

Patient Focus Groups—We conducted 8 focus groups with 41 patients (19 men, 22 women; 4 all-male and 4 all-female groups; 60–90 minutes each). Patients were eligible if diagnosed with HIV and in care, but not yet taking ART (i.e., early in the care continuum); English or Zulu speaking; and 18 years-old or older. Participants were patients visiting the clinic to either obtain CD4 cell count results or ART psychosocial readiness assessments (required prior to ART initiation in South Africa); they were approached and screened in the HIV clinic waiting room.

Patient Interviews—We conducted 60-minute semi-structured interviews with 10 patients (5 men, 5 women) who were diagnosed an average of 2 years prior (SD=3), and averaged 38 years-old (SD=11). Eligibility criteria were similar as for the focus groups. However, interview participants were purposively sampled to capture those later in the care pathway, with substantial delays in returning for CD4 cell count results or readiness assessments. By using slightly different criteria for focus groups and interviews, we obtained a sample that varied by length of delay.

Healthcare Provider Interviews—We conducted 60-minute semi-structured interviews with 11 healthcare providers (2 men, 9 women), including 5 medical providers (2 physicians and 3 nurses) and 6 social service providers (counselors) employed by McCord Hospital. Participants were purposively selected from the provider categories using a clinic list, to maximize variability across categories.

Procedures

Patient focus groups and interviews were conducted in Zulu; provider interviews were conducted in English. Patient interview participants reported demographic information. All focus groups and interviews were recorded, transcribed verbatim, and if necessary, translated. Informed consent was obtained before the session. All study procedures were approved by the McCord Hospital Ethics Committee and Partners Human Research Committee (Protocol #2006-P-001379/25). The Boston Children’s Hospital Institutional Review Board ceded review to Partners.

Qualitative Protocol

Qualitative protocols are shown in Table 1. Open-ended questions about general barriers to care were asked before probes about specific barriers, to avoid bias and allow for emergence and exploration of new topics (Bernard, 1994; O'Brien, 1993). We probed about barriers observed in prior research (Coetzee, et al., 2011; Harris, et al., 2011; Nachega, et al., 2006; Tanser, et al., 2006).

Qualitative Analysis

Data were analyzed using Atlas.ti (qualitative data analysis software) using thematic analysis and methods to optimize reliability between coders (Ryan & Bernard, 2003). Two team members initially read all transcripts and identified key themes (interconnected/overarching ideas) on which to construct a codebook, which listed each theme with a detailed definition and typical examples (Miles & Huberman, 1994). Two raters, overseen by the first author, fractured transcripts into discrete segments and marked areas pertaining to each theme. Each rater independently coded the same 20% of transcripts within each participant category. For these transcripts, inter-rater consistency was very good on all 15 major themes (≥0.70; Mean=0.82, range=0.72–1.00) (Cohen, 1960). Both raters coded all transcripts, with disagreements resolved by the first author. We then examined the distribution of themes within and between participant groups.

Results

Psychosocial Barriers

Overview—Providers and patients agreed that stigma was the main issue faced by newly-diagnosed people with HIV and a key barrier to care engagement and treatment adherence. Although providers recognized that discrimination was a societal problem, they also felt that patients needed to take responsibility for their care by overcoming internal stigma and denial, disclosing their serostatus, and identifying effective social support. In contrast, patients felt that issues related to discrimination were beyond their control, and focused more on challenges stemming from stigma, such as inability to disclose without repercussions.

Internal Stigma—Internal stigma (self-blame/shame about serostatus), was discussed as a primary barrier to care in terms of causes, dimensions, and consequences (Table 2, 1–9). Internal stigma was believed to result from the perspective that patients were responsible for their disease, due to poor choices and immoral lifestyles (Table 2, 1–3). Providers and patients agreed that people with HIV are harshly judged, and that HIV is seen differently than other chronic illnesses, like cancer, in which the person with the disease is not blamed. For example, people with HIV were given less support because, as one doctor said, the HIV was seen as “from [their] own doing,” or as a male focus group participant expressed, because they are a “criminal or a thief.”

Participants discussed the initial shock and denial that the HIV diagnosis engendered, due to the fear of others finding out and discriminating against them (Table 2, 4–9). Denial was seen by many as one of the top issues faced by people newly-diagnosed with HIV. Patients and providers discussed a withdrawal from social support as a consequence of internal stigma and denial. Participants saw this withdrawal as leading people to suffer alone, rather than to seek treatment and support. As one female interview patient expressed, “our beliefs are killing us.” A major stigma-related barrier mentioned by patients and providers was a fear of seeing other patients and providers at their local clinic who resided in the same community and might gossip about their serostatus (Table 2, 7–9). This fear led people to hide their serostatus, even from immediate family, presenting challenges for adherence and utilization.

A key difference between patients and providers was in the attribution of responsibility for health. Several providers stressed the need for patients to take responsibility to overcome internal stigma, in order to obtain medical care (Table 2, 4); as an HIV counselor said, “I think it takes a person and their inner being to be able to be fine or well.” Patients, however, did not express such sentiments.

External Stigma—External stigma was defined as outright discrimination enacted by others (e.g., friends, family members, employers), and included both interpersonal and institutional discrimination (Table 2, 10–17).

Interpersonal Discrimination: Interpersonal discrimination by family members was noted by providers and patients (Table 2, 10–12). They recounted stories of family members not allowing patients to use the same utensils, not wanting to eat food prepared by someone with HIV, and not wanting to touch the body of an HIV-positive family member prior to burial. Patients also told of family members, including partners, who rejected them, telling them to leave or stay in a different part of the house. In addition, patients related stories of community members, employers, and family members who spread gossip about people’s HIV status (Table 2, 13–14). Many of these stories were cautionary tales of other people in their community, rather than about themselves personally, to explain why disclosure was challenging.

Institutional Discrimination (Healthcare and Workplaces): Patients in individual interviews perceived clinics to be rife with opportunities for discrimination (Table 2, 15). Patients spoke of neighbors and others community members who gossiped after seeing them in the clinic. In interviews, patients related the discrimination they experienced from providers and within the healthcare system, including publicly discussing patients' serostatus in waiting rooms.

Discrimination was also feared and experienced in workplaces (Table 2, 16–17). Patients were reluctant to disclose to employers for fear of repercussions. They were concerned about being terminated for missing work due to clinic visits. Some employers did not keep serostatus confidential when told, or treated HIV-positive employees differently, watching for reasons to dismiss them.

In contrast to patients, although providers acknowledged external stigma, they seemed to downplay its effects. They believed that internal stigma was the main issue that hindered patients, and they also did not appear to be aware of (or relate) stories of healthcare-related discrimination.

Tangible Barriers

Overview—Patients and providers showed different perspectives on tangible barriers to care (Table 3), whereas patient focus groups and interviews yielded similar data. Patients had great concerns about the quality of care that they received, mostly centered on inconvenient clinic hours, long clinic queues, not being able to get appointments, and disrespect. However, providers did not believe that such barriers were as insurmountable as patients did. Providers felt that patient denial and stigma were higher barriers than were tangible issues such as cost.

Financial Issues and Lack of Transport—Patients and providers spoke of differences between two types of clinics: free government (i.e., public) clinics, which were located in patients' communities, and semi-private clinics, in which patients paid fees for certain services. Patients preferred to attend semi-private clinics: not only were the wait times shorter, but the quality of care was perceived to be higher. Semi-private clinics tended to be located in urban areas, not patients' communities, reducing the potential to be seen by people patients knew.

Despite the advantages of semi-private clinics, patients spoke of difficulties in paying for services (e.g., CD4 cell count laboratory work) and transport (e.g., shared taxis if they did not have a private vehicle) (Table 3, 2–3; 7–8). If patients did not have enough money for both transport and food, paying for transport would mean foregoing a meal if waiting times extended into the afternoon, and they could not return home in time to eat. Patients who had to take time off from work for clinic visits feared losing pay or being terminated as a consequence (Table 3, 12–13).

Providers acknowledged patients' financial hardships and employment issues (Table 3, 1, 6, 11), and agreed that public clinics had long queues and were less appealing. However, because public clinics offered free treatment and served most communities, providers minimized such barriers (Table 3, 4). Some providers believed that any tangible barriers were a direct consequence of internal stigma and felt that patients should overcome the fear of being seen in clinics in their communities (or of telling their employer). Providers also felt that transport (e.g., shared taxis) was generally available and minimized financial and other costs (Table 3, 9). Only a couple of patients felt that cost and transportation issues were surmountable (Table 3, 5 & 10).

Patient Experience—Patients expressed numerous frustrations with the clinic experience and quality of care, including long queues, lengthy wait times for treatment and/or test results (or lost test results), and inconvenient hours, in which clinics closed prior to serving all patients in the queue (Table 3, 16–17; 19–20; 22–25). Patients had difficulties navigating the hospital space. Patients told stories of waiting in the wrong queue or not being able to find the right queue prior to the clinic closing time, and then having to return. Stories of the most egregious clinic mismanagement were typically at public clinics. Patients emphasized the value in paying for services in semi-private clinics, in which they felt better treated, with a higher quality of care.

Patients felt that healthcare staff across clinic type could have a more caring approach. Patients sometimes felt disrespected by staff, who were described as “short-tempered” and “scolding” in some instances, rather than empathetic and caring. Patients told of staff (usually in public clinics) who took frequent “tea breaks,” made personal calls during work hours, or socialized among themselves while patients waited. Patients sometimes felt helpless in finding out information about appointment delays.

Some providers remarked on such barriers, including long queues and inability of clinics to serve the large volume of patients efficiently, as well as inconvenient clinic hours (during the day on weekdays, when many worked) (Table 3, 15, 18, 21). Only one provider and one patient were openly dismissive of such concerns (Table 3, 26–27). In general, however, provider narratives were thin or absent on this theme, suggesting lack of awareness or underestimation of patients’ challenges.

Discussion

In this study of people with HIV in South Africa, our results suggest a profound mismatch between patient and healthcare provider perceptions of patient barriers. Patients and providers agreed that HIV stigma is a critical barrier in South Africa, consistent with prior research showing high levels of perceived stigma in people with HIV (Kalichman et al., 2009). However, overwhelmingly, providers felt that patients needed to overcome internal stigma as a first step in taking responsibility for care, and appeared to minimize patients’ concerns about the negative consequences of disclosure. Stories about disrespect in healthcare were absent from provider narratives, whereas patient interviews were replete with such reports, in an extension of prior research in South Africa about patient satisfaction with the clinic experience, as well as on clinic inefficiencies (Goudge, et al., 2009; Selman, et al., 2009). Patients discussed how clinic staff did not respect the confidentiality of their serostatus, and of an abrupt style with inadequate communication about delays in test results and appointments, or the purposes of different queues. Although providers recognized that clinics were understaffed, they conveyed impatience about what they perceived to be patients’ excuses for not accessing care, and felt that patients needed to disclose to others to get assistance (e.g., transport) and take responsibility.

Somewhat different information emerged from provider interviews, patient interviews, and focus groups. However, due to limitations of the qualitative methodology, we cannot draw firm conclusions regarding absence of a theme. For example, providers did not seem to be cognizant of the frustrations that patients encountered at clinics. Alternately, they may have been aware, but did not perceive such factors to be a major issue in care engagement.

Implications for Intervention

Community interventions to reduce stigma should be a priority in South Africa. Such interventions can include raising awareness regarding how discrimination is harmful to the community fabric, as well as dispelling myths about HIV due to lack of knowledge about how it is transmitted. Interventions could capitalize on community social networks for spreading information about HIV testing, treatment, and stigma. For example, a popular community opinion leader intervention in China, in which market workers were given information to spread about HIV risk reduction, resulted in decreased HIV stigma (Li, Liang, Lin, Wu, & Rotheram-Borus, 2010).

Interventions could target healthcare providers and systems. A brief stigma reduction using interactive activities (e.g., role plays) for providers in China (Wu et al., 2008) resulted in improved positive attitudes about people with HIV. If such interventions elicit empathy for people with HIV, providers may better understand uncontrollable factors that sometimes shape patients' behavior. More efficient systems to handle patient flow, such as an appointment and triage system for different types of patient concerns, as well as updates from clinic staff about waiting times, could be implemented. Patient navigators might be helpful in checking with patients in queues to ensure they are in the appropriate place, as well as providing updates about delays.

Our research was conducted with a small sample in one semi-private clinic in Durban. Small qualitative samples are not meant to be generalizable, but rather to elucidate a range of factors that may contribute to understanding the problem. Thus, these findings are a starting point for future research and intervention development.

In sum, our study suggests key barriers to care among patients early in the HIV care continuum. Better communication and understanding between patients and providers about challenges faced and potential acceptable solutions are needed to facilitate greater patient satisfaction and retention.

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Table 1

Qualitative Protocol on Barriers to Care for Patient Focus Groups, and Patient and Healthcare Provider Interviews

Question Topic	Question Example
Overview	• What do you think are the major issues facing newly-diagnosed people with HIV?
General Barriers to Care	• What are the major barriers related to getting care for HIV?
	• What kinds of things prevent people from going to the clinics/hospital and end up not receiving medical care?
Psychosocial Barriers	• Is stigma a challenge to getting care, and if so, how?
	• Sometimes we hear stories that some people do not get the support from their family and friends. Do things like that happen?
	• Is lack of disclosure to your partner or to others a challenge to getting care for yourself or for others you know, and if so, how?
Tangible Barriers	• Is lack of transportation a barrier to getting care?
	• What about not being able to get an appointment at the clinic, because the clinic is too busy or not open at convenient times?
	• How do you think the cost of HIV medical care is a challenge or not a challenge to receiving care?

Table 2

Psychosocial Barriers to Care from the Perspectives of 11 Healthcare Providers and 51 Patients

Row	Barrier	Stakeholder Characteristics	Representative Quote
	Internal Stigma		
1	Blame	Doctor	It is considered as a disease of lifestyle and people are discriminated because of their choices…people consider those with HIV to be of poor model values.
2		Patient; Male (Interview)	People tend to judge you if you have HIV. They think that you did not do the right thing and that is the reason you are HIV positive. Therefore, people become afraid to be open about their HIV status.
3		Patient; Male (Focus Group)	You may tell [family members] that you are HIV positive, and you find that they blame you for being HIV positive… They forget that it doesn't matter whether you have been careful or not, and they even forget that you have been in a relationship with someone that you trust, and you have been faithful to your partner but still you got this disease.
4	Denial	Counselor	When we are teaching patients about stigma, we normally divide it into two: we say that it's internal and external stigma. There's nothing you can do with external stigma, but you can do something with internal stigma. Because internal comes from not accepting yourself and when you are not accepting yourself, you think that other people are not accepting you too.
5		Patient; Female; 31 (Interview)	It took me a very long time to accept. I felt as if I could not mix with other people. I was the first person to discriminate against myself.
6		Patient; Male (Focus Group)	People are…scared to visit the doctors when they are sick. And many people are just scared to test for HIV…So, they just don't act and they do not do anything about their illness, and at the same time they are suffering inside because the disease is not quiet. It is affecting them internally and it is not obvious from outside… they are suffering from the stress. These are some of the things that are killing people.
7	Fear of Discrimination	Counselor	Stigma is one of the reasons why people chose to go to the clinics further from home…They choose to go to a place where they think there won't be many people that know them.
8		Patient; Male; 24 (Interview)	When I came [to this hospital], I met so many people that I know. Some of those people are also working here…I was…concerned about what they were going to say.
9		Patient; Male (Focus Group)	The main challenges are in local clinics because people have a problem that their private matters would be known by the neighbors… your neighbors could see you going to the clinic and they talk about it…
	External Stigma		
10	Interpersonal Discrimination	Counselor	When you are at home and you are listening to your family members and they are telling you that one of your family members is infected with the virus we will chase the person away. So even if the person can be diagnosed it won't be easy to disclose to the family members due to the fact that she knows they will be thrown away…
11		Patient; Female; 44 (Interview)	It can prevent you from getting medical care because you do not feel like a human being anymore. It could be as if you have already died even though you are still alive… you observe that your family dislikes…even to be around you… they just keep you in a certain place in the house and you find that you have not bathed, you have not eaten but you are sick.

Row	Barrier	Stakeholder Characteristics	Representative Quote
12		Patient; Female (Focus Group)	My sister passed away…We did not know that she was HIV positive at home because she kept it secret…when my sister went home, my mother was chasing her away… it happened about four times…I had to go home and to tell my mother that my sister is going to stay at home…in the outside room… Even on the day when my sister was going to be buried and we were supposed to bathe her, my mother said that we must not open her coffin because her HIV disease would spread all over.
13	Involuntary Disclosure	Patient; Female (Interview)	This woman came with the child [to the clinic]… After this woman left, the one left behind is now talking…‘This is her sister’s daughter who came for treatment and this child lost her mom and her mom died of this disease as she’s also taking treatment.’…she’s telling people she doesn’t know, it’s not her business…By the time you leave here, your neighbor will be talking about you…
14		Patient; Male (Focus Group)	I disclosed my HIV status to my sisters. But after that they told a non family member and that person started talking about me and he/she told other people.
15	Institutional Discrimination (Healthcare)	Patient; Female (Interview)	One day I went to the clinic…and the sister who came stood there and…talked and talked about us Black people… ‘I don’t know what happened here this month because out of everybody who tested, only two were negative and everybody who was here was positive….So when I…had this STI and the sister shouted at me…“this man of yours, why didn’t you tell him…”…she was Coloured … she shouted at me and after that she went out to wash her hands and she did all the things that show stigma.
16	Institutional Discrimination (Workplace)	Patient; Male; 24 (Interview)	After you have disclosed your HIV status to your employer, things begin to change on how they treat you at work. If you cough, you see that their reaction has changed…By the time you start getting sick, you find that your employer has already distanced him/herself from you.
17		Focus Group Participant; Female	Some employers say that you must go and stay at home when you get sick because your illness is affecting work negatively. They encourage you to resign if you disclose your HIV status. Sometimes they become so harsh and change their attitude…They try to find a way to fire you.

Note: Healthcare provider quotes are shaded grey.

Table 3

Tangible Barriers to Care from the Perspectives of 11 Healthcare Providers and 51 Patients

Row	Barrier	Stakeholder Characteristics	Representative Quote
1	Cost	Counselor	If the service is free, they can come back, but if they need to pay then they have to think about…how they're going to pay. Some are brought here by their relatives, so they need to rely on those people for them to give them money so they can come back again.
2		Patient; Female (Interview)	I did not come back when I was supposed to come back because I didn't have money to come because they told me to bring 200 Rand down there and from there to collect my results.
3		Patient; Male (Focus Group)	It is a problem especially if you are not working and there is no one to support you financially. And even if you try to get some money at home you can see that it is not easy because it means that they must not buy food so that you can go to the clinic.
4	Cost – Not a Barrier	Counselor	Fortunately now the government is providing antiretroviral drugs. Cost is no longer a problem… if and when the time comes where they feel they have run out of funds, they can easily be transferred…to a place where they can get the medication free of charge.
5		Patient; Male (Interview)	If you have medical appointment and you know that you are going to a hospital on this date, you could budget because it's your life at the end of the day. You can do your budget and take out things that are not necessary.
6	Transportation	Counselor	Taxis are there, buses are there, trains are there, but money to take them and those kinds of transport to the hospital or any institution. You have to have money for transport and money to pay for meals.
7		Patient; Male; 41 (Interview)	When I arrived in town, I must get a taxi from town to [the hospital]. You find that I do not have food. I only have transport money to get into the hospital only. This is the major challenge for many people. You may find that they have money to get here, but they do not have money to buy something to eat/food while they are here. He/she will wait until he/she gets home later on and cook his/her samp at home.
8		Patient; Male (Focus Group)	And at some point, there was a report that blood drawn for doing tests get lost. And we were supposed to get CD4 count test results. Then, there was a delay and we were forced to back on the following day. But we could not afford to come back…we were forced to wait for about a week because we did not have money to go back…people do not have money to go to the clinics and also to pay for the service when they get to the hospitals. You find that some people have discovered their HIV status and they have a desire to receive HIV care but they do not have money to do so,
9	Transportation – Not a Barrier	Doctor	There are numerous taxis…and buses and trains coming from every point. I don't think transportation is a problem…I worked in a rural hospital and people used donkey carts to get to my ARV clinic, so I don't think transportation should be a barrier. It's just a stupid excuse.
10		Patient; Male (Focus Group)	There is a lot of transport out there and even if you have challenges of transport in your community, you know where to get transport and you know when it's the right time to get transport. So, you can make sure you are ready and you get transport if you are serious about going to the clinic.
11	Employment	Doctor	A lot of patients cannot get time off work to come to clinic visits, to see a doctor, and our care is structured such that every month for the first three months they have to come and see a doctor. And you know, monthly clinic visits.
12		Patient; Male; 24 (Interview)	I am only free on Thursdays and that is why I am here today. I also have to attend here next Thursday…If I decide to attend on Mondays, it means that I must negotiate with my employer…if my employer does not agree or allow me to do that, it means I have to accept that…the disease would continue to affect me as I would not be getting an opportunity to go to the clinics. I have also noticed that White people undermine this disease, they do not take it seriously and they do not take care of us when we are sick. They just do not care about us. They say that if you start coughing, they would employ another person.

Row	Barrier	Stakeholder Characteristics	Representative Quote
13		Patient; Male (Focus Group)	Let's say you are at the clinic today and they tell you to come back next month…So, you compare the two, you think about work and you think about the clinic, then you decide not to go back to the clinic because you cannot miss work. You may think that you have missed work a couple of times in a month and then you decide not to miss work in the following month.
14	Employment – Not a Barrier	Counselor	A person comes just once a month to the clinic. Even if you are working, everybody who is working is entitled to at least one day off a month in their annual leave. That won't be a problem. It can be a problem if the employer does not know that the person needs to come to the clinic every month. It comes back to that issue of disclosure.
15	Patient Experience: Delays	Counselor	Surely…there will be times where not everybody will get the help that they need at the clinics…because maybe the clinic is short staffed, or maybe the clinic is too busy, or maybe the people who are in the clinic at that time even if there's not many of them but they need extra care so they need extra time to be spent with them by the clinicians or by the health worker at the time.
16		Patient; Female; 44 (Interview)	There are problems especially in the clinics. You find that you have done you CD4 count test and you have already received your results of CD4 count. However, you find that you wait for a very long time; maybe you wait for about six months, without getting your treatment… This means that the disease continues to destroy you while are waiting for [antiretroviral treatment].
17		Patient; Female (Focus Group)	At first, I came with the child and I was in the queue for a very long time and I ended up going back home without any assistance. I was also hungry and the child was also hungry and there was so much delay. So, when I came back the other day, I did not get help and they said they told me that I must return in March. It means I spent transport costs for nothing…So, there are always problems in government hospitals and medical centers where it is free of charge.
18	Patient Experience: Queues	Nurse	But a barrier in government sectors might be time spent in the clinic or time spent in the hospital…They get there very early in the morning, stay for the whole day and maybe get attention late during the day because all those places are full, always full.
19		Patient; Female; 44 (Interview)	Sometimes you sit in a wrong queue because you do not know where to sit. You find that when it is your turn to be seen, they tell you that you are in a wrong queue, and that breaks your heart. Sometimes it breaks your heart in such a way you just decide to go home and tell yourself that you will come back some other time.
20		Patient; Female (Focus Group)	For example, you may find that we are sitting and waiting in the queues, and we have arrived early in the morning, but you find that there is not even a single staff member who is there to help you… You find that the room is full of patients who are waiting and there is no one to help us… the clinic staff keeps on passing by.
21	Patient Experience: Staff	Nurse	Healthcare worker staff attitude - the negative attitude… might cause a barrier for the HIV positive people to access that medical care.
22		Patient; Female	You get [to the government clinic] and wait for the clerk to register you but they'll sit and discuss their stories… the clerk will pay attention to a friend and discuss their stories not us. They'll not pay attention to us… they don't care… if there's an incoming call, they'll answer that, yes! They'll answer their personal calls, talking, laughing… They'll sit and even if another call or three calls come in while you're standing there in front of them.
23		Patient; Male (Focus Group)	Okay, usually you go early in the morning when you go to the clinic and you wait for the whole day in the queues for help. And sometimes you find that the clinic staff is taking tea break at 9AM. And you have been waiting since 7AM till late, but you find that they are just sitting and discussing personal matters whereas we are waiting for their help… You find that you spend the whole day at the clinic but you do not get help in the end.
24		Patient; Female; 44 (Interview)	Some of the health care workers speak in a nagging way. Therefore, some people get annoyed and stop going to the clinic as they feel that they are going to deal with such health care workers who talk in a

Row	Barrier	Stakeholder Characteristics	Representative Quote
			nagging way… It could be better if they can stop scolding at patients… I think the doctors should be more caring.
25		Patient; Male (Focus Group)	I think there is lack of communication between the clinic staff and patients. For example, we could be sitting and waiting in the queues and we see staff members passing by, and we do not understand what is going on… there is a wall between the staff members and patients. For example, they could only say, “next or the next patient, or they say you must wait for few minutes we have a tea break.” … It is frustrating … Sometimes, you wait for a very long time and then you decide to go back home because they are not helping you. And you do not even understand why you did not get help.
26	Patient Experience – Not a Barrier	Doctor	We have a waiting list of about three weeks now. I don’t think that that would be an excuse because getting an appointment as a first initial visit it’s a walk-in system in this clinic. So number one, that’s not a problem. And number two, is if you are on treatment here in this clinic and you do want to see a doctor then you are allowed to make an appointment to come in and see a doctor. And if you can’t, there are always government casualties, provincial hospitals, private doctors, you can go to anyone if you have a problem and you can always get advice. So not necessarily with us.
27		Patient; Male (Interview)	You cannot leave without getting help at the clinic. It never happened.