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Stumbling Blocks at the Clinic: Experiences of Seeking HIV Treatment and Care in South Africa

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Abstract

Prompt antiretroviral therapy (ART) initiation maximises the therapeutic and prevention benefits of a treat-all strategy for HIV therapy. Using in-depth semi-structured interviews with men and women 18 years and older (N = 41), who were highly motivated and seeking treatment, this study examined salient factors that were associated with delays in treatment access and initiation. Results revealed clinic-related barriers including an onerous, inefficient multi-step process to initiate ART. Participants experienced additional delays due to difficulties accessing care (e.g., being turned away from clinics and referred elsewhere) and health service challenges. Health service challenges included difficulty securing appointments, administrative mistakes (especially lost clinic folders and test results), difficulty navigating the clinic system (e.g., failure to collect a queue card or waiting for incorrect services) and negative clinic-patient interactions. Overall, there

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Conflict of interest All authors declare that they have no conflict of interest.

Compliance with Ethical Standards

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. The Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town provided study approval (Ref: 849/2014).

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

was a pervasive negative perception of clinics. Results strongly indicate the need for more patient-centred models of care and the need to reduce unnecessary patient-days at clinics.

Keywords

Linkage to care; HIV care continuum; Antiretroviral therapy initiation; Barriers to treat-all; HIV treatment access

Introduction

South Africa, the country with the largest HIV epidemic [1], has recently adopted a treat-all approach for antiretroviral therapy (ART) whereby all HIV-positive individuals are referred for treatment regardless of CD4 count [2, 3]. The treat-all approach aims to maximise both the therapeutic [4, 5] and prevention [6–8] benefits of early ART. For the treat-all strategy to be effective, it is necessary to link HIV-positive individuals to care and treatment as efficiently as possible.

Several studies from South Africa prior to implementation of the treat-all approach indicated that ART programs experienced poor rates of linkage to care and treatment [9–14]. Linkage to care was particularly low after community-based testing and referral for treatment from services such as mobile health clinics, compared to clinic-based testing and referral [15]. Community-based testing will be important under a treat-all approach due to the need to find and diagnose asymptomatic HIV-positive individuals. To be successful, the treat-all approach will require greater innovation and efficiency in testing, referral, and linkage to care and treatment services.

Studies from sub-Saharan Africa identify an array of individual and community level barriers to ART initiation including stigma [16, 17], relative good health [9, 18], poor education and knowledge [17, 19], denial of HIV status [17, 20], and lack of money or time [11, 20, 21]. Clinic-related delays to ART initiation due to education and counselling activities associated with preparation for ART [22, 23] may exacerbate individual and community level challenges to ART initiation and contribute to significant patient attrition between ART-eligibility assessment and treatment uptake [10, 24, 25]. In South Africa, pre-ART counselling became the norm with the aim to improve long-term adherence [23, 26]. This approach has typically involved multiple clinic visits [22], and a wide range of practices and activities for ART preparation have been documented [23].

This study sought to improve our understanding of factors that cause delays to ART initiation among individuals referred to HIV treatment clinics from a mobile health clinic in Cape Town, South Africa. Using in-depth qualitative interviews with individuals enrolled in a pilot randomised controlled trial examining the feasibility and acceptability of a conditional economic incentive [27, 28] to improve the uptake of ART, we aimed to shed light on salient treatment barriers by including the experiences of individuals who did not start treatment following the offer of a financial reward. While patients reported a range of concerns and obstacles, clinic-related barriers emerged as the predominant theme from the

interviews. In this article we present data on patient experiences of the process of initiating ART and the variety of clinic-related challenges, and the complex interplay between them.

Methods

Data

We conducted in-depth, semi-structured, face-to-face interviews with men and women 18 years and older enrolled in the iLink Study, a pilot randomised controlled trial (RCT) testing the use of a conditional economic incentive to encourage ART initiation. From April 2015 to May 2016 the iLink Study enrolled individuals diagnosed HIV-positive and referred for ART by a mobile health clinic in Cape Town. ART-referral was based on National Department of Health guidelines, at that time: a CD4 count ≥ 500 cells/ μ L [29]. The mobile clinic offers free screening for several health conditions to a predominantly black Xhosa-speaking African population residing in resource-poor areas. In the iLink study, 86 eligible participants completed a baseline survey and were randomly assigned to the control or intervention group. The control group received the standard of care: telephone counselling by the mobile clinic staff to encourage linkage to care. The intervention group received the standard of care plus a voucher that could be exchanged for R300 cash (approximately \$23 at the mid-point of study enrolment) if ART was started within 3 months. After ART initiation, participants in the intervention group met with the study staff to verify ART initiation and receive the incentive. For all other participants, ART initiation was assessed during a follow-up survey conducted 3 months after study enrolment.

The sample frame for the in-depth qualitative interviews included all iLink study participants who were successfully contacted for follow-up surveys ($N = 64$). Forty-one of these 64 participants were successfully recruited for in-depth qualitative interviews (Fig. 1) from May 2015 to September 2016. Reasons for not participating in the in-depth interviews included failed contact attempts; participants unavailable; participants not arriving at scheduled interview; and participants moving away from the region.

For participants in the intervention group who initiated ART within 3 months, in-depth interviews ($n = 14$) were conducted immediately after they received the incentive. For all other participants, in-depth interviews were conducted as soon after the 3-month follow-up as possible. Written informed consent was obtained prior to initial study enrolment and at the beginning of the in-depth interview. The interview guide was designed to explore (1) concerns and challenges with starting ART, (2) the process of starting ART, and (3) experiences at the clinic. Interviews were conducted in Xhosa by trained and experienced interviewers.

Analysis

Audio recordings of interviews were professionally translated and transcribed into English. Four team members developed a codebook through an iterative process of reading transcripts and refining the codes. Codes were based on emergent themes from the transcripts. Interview transcripts were imported into Nvivo (QSR International Pty Ltd. Version 11, 2016) for analysis. Two team members each coded a third of the transcripts, with

discrepancies discussed and resolved to refine the codebook and coding, and the principal investigator coded the remaining transcripts. An inductive, team-based approach was used to identify themes from the interviews, with the study team meeting to discuss emerging themes.

Results

Characteristics of the participants who completed in-depth qualitative interviews ($N = 41$) are presented in Table 1. A third of the sample was male. The majority was younger than 40 (73%) and had not completed Grade 12 (71%). Participants were generally very poor with 83% living in an informal dwelling/shack. ART readiness and motivation was very high and 93% of participants expressed the intention to start ART within 30 days. However, only 61% had started ART by the time of the in-depth qualitative interview. Just over a quarter of the individuals interviewed had been offered an incentive for starting ART, but had not yet started treatment.

Three overarching themes on clinic-related barriers to ART emerged: (1) inefficient multi-step procedures to initiate ART; (2) difficulties accessing care; and (3) health service challenges. While these themes are presented separately, there was often a complex interplay between them, and several participants experienced multiple barriers. Quotes illustrative of the themes are presented in the text along with the following characteristics: gender, age, RCT group assignment, and whether the individual had started ART or was ART-naïve (i.e., a participant who had not initiated ART by the time of the in-depth interview). Additional quotes reflecting thematic results are provided in Table S1, Supplemental Digital Content.

Inefficient Multi-step Procedures to Initiate ART

Most participants were poor, walked to the clinic, and therefore generally chose the closest clinic to where they lived. Due to long clinic queues, participants typically left home for the clinic very early, between 5 a.m. and 6 a.m., and spent the whole day at the clinic for each visit. For the vast majority of patients, the first visit to the clinic resulted only in an appointment date being made to see a counsellor.

I want to start treatment but I am just confused...you just queue the whole day when it's your turn they give you another appointment date. (Female, 45, control group, ART-naïve)

Moreover, it often required multiple clinic visits to secure an appointment with a counsellor or a wait of many days for the appointment.

I went to the clinic on 11 November last year, then as it was holidays on December they ask me to come again in January. (Male, 35, intervention group, on ART)

After receiving an appointment date, patients generally underwent three counselling sessions before returning to collect their treatment, as described below:

At the clinic it's a long process you have to be patient because I have to wake up early like 5 a.m. because it would be full of people there. So when you got there, they would start at 8 a.m. maybe you would come back home at 4 p.m. and for the

first day you have to see a counsellor and they will give you another date to go there to see the counsellor again so that they will counsel for the second time so you have to be patient if you want to go to the treatment. Then on the third day they will counsel you for the third time whereby you are going to get your medication so you have to be patient. (Female, 28, intervention group, on ART)

However, it was also not uncommon for patients to complete 4–6 clinic visits before starting treatment, as described by the patient:

I went the whole week; the whole week I had been going to [Clinic A]...Everyday!
(Male, 30, intervention group, on ART)

Other participants described how this long process happened, with pre-counselling, two subsequent counselling sessions, a refresher session and then the actual initiation of treatment. The multi-step process was difficult for patients to complete for several reasons, including the effort involved in walking to the clinic due to lack of transport money; fear of being robbed while walking to the clinic; getting time off work; time needed to search for employment; feeling tired and ill and spending the entire day at the clinic without food; and attending clinics far from home due to stigma-related concerns. For example, one woman was not willing to disclose her status at work in order to explain the frequent absenteeism required of the process:

After that I was given another appointment so that I can sign to take treatment, that was the date that get me into trouble at work because each and every week I am absent. So I couldn't go to the clinic for my appointment. (Female, 32, intervention group, ART-naïve)

In some instances, patients gave up on treatment because they could not tolerate the delays involved:

I won't lie but what made me delay in going to the clinic were the long queues, nothing else.... I would go and when I get there, there would be those long queues and then I would leave. (Male, 30, intervention group, ART-naïve)

Not surprisingly, patients suggested making the process less onerous as a strategy for helping individuals to start ART:

I think they should stop giving us many appointments, if you go for the first time then the next following appointment you get help then the next time they give you treatment instead of skipping. (Female, 45, control group, ART-naïve)

Overall, these logistical complications and delays negatively influenced the respondent's ability to successfully initiate ART at the time of the interview.

Difficulties Accessing Care

Prior to starting the process described above, participants had often already experienced delays due to being turned away from a clinic or being referred elsewhere. Patients were often sent to multiple different clinics before they successfully commenced treatment. As a patient related:

I started to go at [Clinic B] and I thought I would take it there. So they gave me another date to come back there but when I was sent to that room where I was supposed to start, they said no I should not start to take it there. Again they sent me to [Clinic C], even there, they said I cannot start it there because I don't belong to them, then it's whereby I went to [Clinic D] and they accept me. (Female, 21, intervention group, on ART)

Participants were commonly told that they were being referred elsewhere because there is a clinic closer to their home. High levels of uncertainty among patients about where to receive HIV care and treatment services therefore resulted in many onward referrals as participants often first visited a clinic that was not the one closest to their home:

I went to [Clinic F] because the one here at [Clinic E], I was told, is paediatric...I would have to use public transport to get to [Clinic F] while the clinic that is close by I can just walk. (Female, 29, control group, on ART)

Uncertainty about where to receive HIV care and treatment services also led to participants first visiting a clinic where ART services were unavailable, or unavailable to them:

I once went to the [Clinic G] here in Khayelitsha but it turned out that I do not qualify to be part of it because I am 30 years and they take people who are not older than 24 years of age. (Male, 30, intervention group, ART-naïve)

Other barriers to care varied widely. One man, for example, was turned away from the clinic closest to where he was living because the shack he was living in was located in a new housing area that had not been assigned addresses. Unstable or unregistered housing among township residents is common, and functions as another barrier for care. Another woman tried to start the process but found the clinic staff on strike:

I was disturbed by my mother's illness back home in the Eastern Cape. So when I went to the clinic to inform them and to try and get a transfer to get my treatment in a clinic nearby my village back home, the nurses were on strike. So that is why I delayed and that is when I decided to start afresh when I returned. (Female, 48, intervention group, ART-naïve)

Health-Service Challenges

Experiences at clinics were characterized by treatment delays due to several factors relating to the clinic system and quality of care.

Difficulty Navigating the Clinic System

Some participants had difficulty navigating the clinic system themselves. One participant, for example, misunderstood the queuing process, which resulted in her not receiving care and opting for a different clinic:

I went with that letter but the mistake I have done is that, I just get inside the clinic without getting the card to queue. So it's whereby they chased us away and I have decided to go to [Clinic C] because I know that they are not chasing anyone. (Female, 21, intervention group, on ART)

Other participants followed the steps to ART-initiation outlined by a health provider only to be redirected to another provider, indicating inconsistencies among clinic staff in the requirements for treatment. One woman, for example, spoke of being repeatedly referred to different counsellors within the clinic:

Because there are three doors there where the counsellors are stationed and the staff there would say which door to go into and when I went to that door, that counsellor would tell me to go to the next door and that counsellor will also refer me to the next one and would ask why the first counsellor didn't counsel me. And when I would go back to the previous counsellor then that counsellor would have already left and they would give me another appointment date; they are the reason that it took me so long to actually start with my treatment. (Female, 29, control group, on ART)

Another participant completed all counselling sessions and was referred to the pharmacy at the clinic to collect her medication, but was denied treatment by the pharmacist because her records indicated that she had told the counsellor that she drank alcohol. She gave up on the process:

I then returned to the clinic for the third time and that was when I went to the pharmacy where I was to actually get my ARVs but the lady there sent me back. She looked at my folder and she saw that I had attended all the counselling sessions then she asked me if I smoke, I said yes, I use Snuff tobacco and she asked if I take alcohol, I said yes I do drink alcohol. The she said no I must go back to the person who sent me to her but I did not ask her why so off I went back to the person who had referred me to the clinic in the first place.... they gave me another date but I didn't go because I also got tired of the back and forth as it is also far for me to travel there, only to sit there the whole day. (Female, 38, intervention group, ART-naïve)

Difficulties navigating the treatment process were compounded by poor health literacy, with participants often not understanding what they had been told at the clinic and the health services received or prescribed. Consequently, they sometimes left the clinic uncertain, and sometimes anxious, about what was expected of them or what was going to happen next. One man spoke of receiving no information or HIV care after providing the clinic staff with his referral letter for ART.

...when I got to the clinic; I got tested for TB. They never said anything again to me about HIV. (Male, 24, control group, ART-naïve)

In another example, a woman expressed her anxiety surrounding a referral for a procedure that she did not understand:

They also told me ... that I would have to do a pap smear, I did not know what a pap smear was so I was wondering what they would do to me because I had no idea what it was. But I just decided that I should just do what would be best for my own life. (Female, 23, intervention group, on ART)

Administrative Mistakes

It was common for patients to report additional delays due to administrative issues such as lost folders and especially lost test results.

I mean the day I went for my treatment, I sat there the whole day waiting to be called but they did not call on me and eventually they would say that they cannot find the folder and they have to start afresh, go to the nurse, explain to her what is going on and so forth so there is a lot of delays at the clinic. (Male, 35, intervention group, on ART)

Lost test results sometimes led to multiple additional visits to the clinic and were a major barrier to timely initiation of ART:

I was treated badly as I was very weak by the time I went for results as they always told me that they can't find the results it was not easy because I was forcing myself to go at the clinic.... It was TB results as I had a letter request to check a TB, so they ask me to give them a sputum on Wednesday then come for results on Monday. When I came back on Monday they said that my results are not available I must come back next week Tuesday, on that Tuesday they ask me to do another sputum, I think I cough for six times to get my results. On my mind I was about to change the clinic if my results were not available again...they said that sometimes the results exchanged with other clinics at the lab. (Female, 24, intervention group, on ART)

Experiences and Fears of Negative Clinic-Patient Interactions

Several participants reported negative interactions with clinic staff members. The consequence was generally a change in clinic and sometimes the main reason for not having started ART. When asked why he had not started treatment, one man answered:

It's because I want to change the clinic and I don't want [Clinic H] as they gave me another date and [they] shouted at me. (Male, 25, intervention group, ART-naïve)

Other experiences included:

I stay in Gugulethu and after I was diagnosed, I went to [Clinic C]; I went to ask where I should go as I was coming for treatment for the first time; I do not know if I went there at the bad time, whether the nurse was angry or was stressed by her personal problems but she was so rude, it was hurtful... So I turned around and left... I used to hear how rude the nurses are but never realised until I went there myself. (Female, 30, control group, on ART)

While some participants reported a positive experience at the clinic, the perception that they were going to be treated badly at the clinic was pervasive.

I had expected that a person who has HIV is not someone who would be treated well so I was expecting bad treatment and I expected to be scolded/shouted at by the nurses as to why I had stayed so long before coming to the clinic. (Male, 25, intervention group, ART-naïve)

In some cases, these perceptions created anxiety:

I was worried that they would ask why I take long until CD4 count goes down like this, and I thought they would insult me...I was worried that they would say you come now as you are a crock look at your CD4 count is very low...They shout a lot at the clinic...I used to see other patients when they are shouted at by nurses asked them why you didn't come on your date? (Male, 35, intervention group, on ART)

In one case negative perceptions of the closest clinic was the reason a women selected a clinic further from home, even though she experienced problems finding money for transport:

No, I don't like to go there because each and every day it's full as if there is no care. (Female, 45, control group, ART-naïve)

For another woman the fear of being stigmatised at the clinic delayed ART initiation:

I went to the clinic, but on the way, I was afraid and decided to turn back home...I went to the other nurse with that letter and she told me to take it to the admin, that is when I decided to go back home without going there...I wanted to speak with the nurse not the people at the admin...I thought they would judge me or say something else. (Female, 19, control group, on ART)

Discussion

This study revealed a complex array of clinic and process-related factors that make it difficult for patients to initiate ART in a resource-poor area of Cape Town, South Africa. Even the best-case scenario when it came to receiving treatment, involving no additional delays, was an onerous process. Patients often had to attend the clinic five or six times before being able to start treatment. Extremely crowded clinics often meant leaving home before 6 a.m. each day and spending all day at the clinic each time, a process that for many would take up to 40–60 hours. The experience of long waiting times is consistent with the findings of other studies involving HIV-positive individuals in South Africa [30, 31]. Among our sample, difficulties with completing the process were compounded by structural barriers, such as work commitments and lack of money for transport, that are common impediments to linking to care [11, 14, 32, 33]. Difficulties associated with walking to the clinic—such as fatigue and illness, fear of local gangs, and bad weather—further highlighted the burden of multiple clinic visits.

Of particular concern is that the best-case scenario was uncommon. Some patients experienced long delays in getting a first appointment with a counsellor, which is consistent with studies from elsewhere in South Africa [34]. Furthermore, numerous patients started the process at one clinic and then started again at another for several reasons. It was also common for administrative mistakes to cause delays. Overall, there were pervasive negative perceptions of clinics with participants expecting bad experiences ranging from poor quality services to stigmatising reactions from clinic staff (including front office staff at the registration desk, counsellors and nurses). This finding is consistent with several other studies conducted in sub-Saharan Africa [20] and South Africa [34]. Although some patients ended up having a very good clinic experience, the anticipation of poor treatment was often

well founded and added anxiety to a stressful post-diagnosis period and delays in receiving treatment.

For many participants the barriers to ART initiation described here did not occur in isolation, but rather combined to compound difficulties in starting ART. For example, one strategy adopted in response to a bad experience at a clinic, or administrative problems, or fear of being stigmatised was to try a different clinic. Often this clinic was much further from home and compounded the problems experienced with undertaking the multiple visits required to start treatment. Furthermore, the second clinic sometimes referred the participant elsewhere. Participants could therefore have to re-start the onerous processes involved in obtaining treatment multiple times.

Experiences of clinic-related barriers were evident for participants in all groups in our study, with no obvious difference between groups. This indicates that patients who initiated ART had overcome these challenges rather than avoided them. Additional research on how patients manage clinic-related delays to ART initiation may shed light on interventions to improve uptake of treatment.

The results from this study should be interpreted within the context of the study limitations. The extent to which these findings can be generalised to other, especially wealthier, patient populations is unclear. In addition, participants were drawn from a relatively small geographic area and the descriptions of the clinic services may not be applicable to other regions. Given that the healthcare system in the study region (Western Cape Province) is relatively robust compared to other provinces in South Africa [23], there is the potential for clinic-related barriers to be even more acute in other settings and additional research is required. A further possible limitation is a focus primarily on patient perspectives. This focus may result in a bias towards patient perspectives with a need in future studies to elicit additional perspectives from clinic providers.

Our results have several policy implications. There is a need for a more patient-centred process for ART initiation. To achieve such a process several interventions are required. Within the context of overcrowded clinics, the number of clinic visits required is a barrier to ART initiation that needs to be removed or reduced. Same-day ART initiation [22, 35] and more efficient models for patient ART preparation [36] could be effective. Recent policy and service delivery guidelines for fast tracked initiation counselling in South Africa should be implemented by clinics as quickly as possible [37]. Alternative models of differentiated care should be considered. For example, community based counselling for ART preparation may be feasible for patients referred for treatment from mobile health clinics.

Interventions are also needed to make sure patients can navigate the clinic system. For example, during community-based referral for treatment, patients should receive counselling on precisely which clinics they can visit. This should include a discussion both of the clinics closest to patients' location of residence and of the best alternatives should the patient not want to visit a clinic close to home. Within clinics, a reduction in the number of administrative mistakes, particularly the loss of test results, will also lead to fewer unnecessary days spent at clinics.

It is also an imperative that the quality of care and efficiency of services improve and instances of discrimination and stigma be eradicated. Since perceived stigma (perceptions that people living with HIV are stigmatised, in this case, at the clinic) is a product of social learning, even isolated experiences of patients being stigmatised can create a pervasive perception that the clinic staff will treat people living with HIV badly. The negative effect of such perceptions on patients highlights the need to rebrand clinics as places where people will be treated with dignity and respect and receive non-judgmental services.

From a health systems perspective, the sheer number of clinic visits being made by patients, especially unnecessary ones, exacerbates problems of overcrowding and waiting times, with the associated human resource shortages. Reducing the number of clinic days for patients will be especially important in order to successfully adapt to a test and treat approach, which will likely see a greater number of individuals starting ART.

Conclusions

Delays in ART-initiation come at high personal and public health costs. Results from this study highlight an array of clinic-related factors that cause delays for individuals who are highly motivated and seeking treatment. We urgently need to address these stumbling blocks before a full scale-up of the test and treat approach leads to increasing numbers of individuals seeking treatment. Results strongly indicate the need for more patient-centred models of care for HIV-positive individuals referred for ART.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Fig. 1.

Flow chart of study participants recruited to in-depth qualitative interviews. Interviews marked '*' were conducted after the study's 3-month follow-up survey. The term 'ART-naïve' is used to describe participants who had not initiated ART by the time of the in-depth interview

Table 1

Characteristics of the qualitative study sample (N = 41)

Characteristics	% (n)
Male	34 (14)
Black African	95 (39)
Age range (years)	
18–29	34 (14)
30–39	39 (16)
40+	27 (11)
Education (completed)	
Grade 9	27 (11)
Grade 10 or 11	44 (18)
Grade 12	29 (12)
Employed	34 (14)
Informal housing/shack	83 (34)
Knows people living with HIV	85 (35)
ART knowledge	
Heard of ART before study	90 (37)
ART cannot cure HIV	87 (36)
ART is lifelong	95 (39)
ART readiness	
Very ready to start	88 (36)
Very motivated to start	90 (37)
Very confident of positive health effect	88 (36)
Intend to start in 30 days	93 (38)
On ART at the time of the interview	61 (25)
Offered incentive and ART-naïve ^a	27 (11)

^a At study enrolment these individuals were offered a R300 cash incentive to start ART within 3 months