



Community Perceptions Affecting Uptake & Retention On Antiretroviral Therapy By PLHIV:

A Qualitative Study Among Residents Of An Urban Informal Settlement In Kenya

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Summary

INTRODUCTION

Lack of HIV treatment and loss of follow up measures is associated with high mortality among persons living with HIV (PLHIV) in sub-Saharan Africa. Especially in resource-limited populations. Respondents diagnosed with HIV through a home-based testing and counseling program in an informal settlement in Kenya, were referred to health facilities of their choice for antiretroviral therapy (ART). This qualitative study explored the community's experiences and perceptions on factors associated with ART uptake and retention.

METHODOLOGY

Using convenient purposive sampling, we recruited 46 adults (21 women and 25 men) among them HIV infected and non-infected residents of the Kibera informal settlement in Nairobi, Kenya. Using a standardized discussion guide, six focus group discussions of 6-9 individuals were conducted. Discussions were recorded verbatim and complimented by tape recording to ensure accuracy. Transcription was done and coding done using a *Priori codes*. Thematic content analysis was done using *Atlas 3.0*.

RESULTS

Availability of many health facilities offering HIV services in Kibera informal settlement facilitated access to and uptake of ART. Respondents preparation procedures that prevented same-day ART enrolment were often perceived as denial of treatment.

“They talk too much of treatment and when you go you are turned away” Said one respondent. Reported perceived poor staff attitude, Rudeness, Judgmental behaviours and Delays, were often perceived as lack of respect for Participants were reported to hinder retention in ART services.

“He will look at your physical appearance, put your card aside and ask his colleague whether tea is ready” Participants disliked adherence counseling with written commitments after missed appointments and often felt that these measures too reflected lack of respect by health care providers. They wanted to cancel treatment because they said we had to commit ourselves by signing....”



CONCLUSION

Individuals diagnosed with HIV generally accessed HIV treatment facilities following referral after HBTC. Participants perceived some standard treatment procedures. Reckoning Staff behavior and Communication as barriers hindering retention on ART. Supportive interpersonal relationship strategies between Respondents, providers and innovative patient-centered treatment plans and adherence counseling models should be adopted in treatment programs. This will promote uptake and retention of ART in communities.

Key Words:

HIV infection, retention in ART, adherence counseling, psychosocial and communication barriers, Responded satisfaction.

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Introduction

Early initiation of antiretroviral therapy (ART) in persons living with HIV (PLHIV) reduces the rates of sexual transmission of HIV 1, clinical events and improves the quality of life of the individual [1]. Lack of treatment and loss to follow up is associated with high mortality in sub-Saharan Africa especially among resource- limited populations [2].

Fear of stigma and discrimination in the PLHIV's household, work place and health care setting negatively affects access to care and treatment [3, 4, 5].

Additionally, studies have reported structural barriers including distance to the health facility, poverty, poor quality of post-test counselling to understand the disease and benefits of ART [6]

Poor linkage to care and treatment (where clients who are referred do not get to the facilities) to be associated with lack of access to care and treatment [7,8,9].

In one study of HBTC in western Kenya, as low as 16% of those who had tested HIV positive had been linked to care in a median of a 3 year period [10].

In Kenya, community health workers have been deployed to improve linkage to care and treatment by encouraging the newly diagnosed HIV infected patients to access and remain on care and treatment [11].

In addition to barriers to uptake of services, studies in Kenya and sub-Saharan Africa have reported decline in retention in care and treatment from 86% in 12 months to 72 % in 5 years [2, 7, and 12].

Reported barriers to loss to follow up include poor staff-client interactions, staff shortages long waiting time and need to attend several clinic appointments before initiating treatment [13].

Innovative strategies including the use of phone reminders, home visits and the performance of multiple steps on a single visit at the clinic [12] have been used to help keep clients in care and treatment.

The World Health Organization (WHO) has recommended implementation of a 'test and treat' strategy (where an individual diagnosed with HIV is initiated on treatment on the same day or soon after regardless of their CD4 count) in order to mitigate many of the barriers and challenges to treatment access and also facilitate faster transition from care to treatment.

Clinic routines and certain HCW practices including color-coding of patients' medical records to signal their health status and health workers counting pills without the use of gloves have been reported as additional barriers [14].

A study from South Africa showed that patients' perceptions of the quality of care they receive, reveal what they regard as most important for them, as well as give insights on their experiences that influence their service uptake and retention [15].

Understanding the collective effects of poverty and difficult socio-environmental conditions which increase the informal settlement residents' vulnerability to poor health outcomes is important; but it would also be important to understand their perceptions of the services they are offered.



No studies have documented the informal settlements residents' perceptions of the services they receive in the health care facilities and how these perceptions might influence their health seeking behavior and retention on ART by PLHIVs.

This paper seeks to explore the combined community members' experiences as they accompany family, friends or neighbors to seek HIV services and the PLHIV's experiences and perceptions as they seek health care in the ART clinics in a large informal settlement in Nairobi.

Methodology

Study Site and design

This study was conducted in Kibera informal settlement in Nairobi between August and December 2012. The settlement has high population density and is characterized by low economic status with poor sanitation, overcrowding and houses made of tin and mud.

There are high rates of unemployment among young adults who remain idle and often engage in HIV-associated risk behaviors like high alcohol consumption, prostitution, child labor and petty offences [16].

The informal settlement was chosen because the residents had received community-wide HBTC services in the last 18 months prior to the study. This settlement has many non-governmental organizations (NGOs) that provide free HIV care and treatment services as well as small individual-owned clinics who charge for services rendered.

A qualitative explorative and descriptive design was used to explore the combined community and the PLHIV's perceptions and experiences encountered when the community members accompany family, friends and neighbors to seek HIV services. Or as the PLHIVs seek services from the comprehensive care clinics after a diagnosis of HIV through HBTC.

Population and sampling

This is a population where because of the proximity of dwellings, the residents have open interactions with each other, know each other and influence the behavior of each other either positively or negatively.

Many of the residents are found engaging in conversations with each other in the neighborhood most of the day.

Non-probability convenience sampling was used to select participants. Eligible participants were above 18 years of age, able to speak either English or Kiswahili. Residents of Kibera for the last 2 years, were familiar with the neighborhood health facilities and were willing to participate in focus group discussions (FGDs).

HIV status was not asked because of confidentiality and therefore was not a criterion for inclusion.

Data Collection

A total of six FGDs were conducted with a total of 21 women and 25 men; each focus group consisted of between 6-9 participants both male and female.

To be culturally sensitive as informed by the community members themselves, the participants were divided into age groups 18-30 and 31-50 years per focus group to allow for free expression. FGDs were conducted in a private location using a standard discussion guide developed for this study.

Questions were designed to elicit open-ended responses, encourage flexible discussion, and enable probing.

During the discussions, data were captured by note takers and tape recording. Tape recording was used to not only supplement the notes but also provide information not otherwise captured such as the tempo of the discussion.

Ethical Clearance

Ethical clearance was obtained from Kenya Medical Research Institute's Ethical Review Committee and the United States Centers for Disease Control and Prevention (CDC) Associate Director for Science.

Each participant gave written consent and was assigned a code for confidentiality. Each group also provided verbal consent for note taking and use of audio recording during the discussions.



Data Analysis

All the transcripts from the six FGDs were read through carefully one after the other to gain understanding of the data. Using priori (potential) codes list, coding was done by reading through the text twice and summarizing each response in the text by assigning a word or phrase description that best answered the research question [17].

Repeated or recurring words or phrases were reduced to a single code.

This list of key words/phrases were entered into Atlas 3.0 and tagged to their associated segments of the merged text that best addressed the research question to ensure that no segment of responses was missed.

Through final codes we identified recurring patterns to arrive at the final themes from the text.

The emerging themes developed for analysis included knowledge, choice of facility, benefits of ART, time from testing to accessing ART, and HCW communication, behavior and practices.

The tagged text segments were then reviewed and the most interesting quote, verified by the tape recording selected to represent the segment in answering the research question.

Results

Theme

1: Knowledge, benefits and choice of ART facility

The participants were unanimous that the reason for HIV testing is to start treatment early if they are diagnosed with HIV.

They mentioned up to eight health facilities within the informal settlement and its environs including those that provide HIV treatment for free and those that charge for services and which of the two offered incentives including food, soap and free ambulance and hospitalization services for families when they needed.

The majority of participants reported that the choice of

the facility was largely determined by the incentives offered in a given facility. Overall, HIV treatment was reported to be very important and was valued highly by the participants.

*“... it (treatment) reduces the burden in a family such that when one is positive and starts taking drugs when he/she is still strong there is no day that you will be down especially if you are a bread winner
(Female 31-50 years).*

The majority of participants reported they preferred facilities and organizations that offered food in addition to ARVs and also covered other health needs like providing free ambulances and hospitalization when they or their family members are critically ill. One organization was particularly mentioned for offering all the above.

*“Some places they give donations like milk, porridge flour and even food stuffs which make you happy”
(Female 18-30 years)*

*“It is just that you people are not interested in helping us. This is because others give us millet flour but you just give us medicine. You guys are just concerned about AIDS. To be honest, if you compare your services to that of others, then you are not even number 5, food is important”.
(Male 31-50 years)*

*“If you use medicine without food then you will die”.
(Female 31-50 years).*

Theme

2: Timing from HIV testing to ART uptake.

All participants reported unanimously that although most people who test HIV positive in the settlement eventually access the treatment services, they do not do so immediately upon diagnosis and referral.

The time between diagnosis and access to care and treatment was reported to be one month after testing. (It was explained that the one month is a general assumption and perception based on the residents' knowledge of the appointment intervals given to those



on care and treatment).

*“After a month he/she will be going for check for.
You are given a date every month you will be going”*
(Male 31-50 years).

Most participants reported that the majority do seek additional testing from different places to confirm their diagnosis prior to seeking enrolment in an ART clinic.

*“after they confirm, they take too long
to go for medicine,
they wait until they see signs,
that’s when they go to the doctor
and say they were tested
and found positive”*
(Male 31-50 years).

The majority of participants reported that people seek ART when they become sick

“When they become sick they go running”
(Male 18-30 years).

Other reasons for delay in seeking care and treatment is to avoid becoming fat

“Others fear due to rumors that ARVs are big fat”.
(Female 18-30 years)

The participants reported that although CHWs helped in encouraging people to seek treatment, individuals feared to go to the health facilities in the neighborhood because “they know each other”.

*“If I have ‘it’ and I go for ARVS in PAG
(one of the facilities within the settlements),
and no one knows that I have ‘it’
the way I am pretty, when I get there I find my
neighbor who has come to take his drugs and he is
sickly, when he leaves he would know that I am sick
and would say in the village
(Female 18-30 years)*

Theme

3: *HCW communication and behaviors at the health facilities.*

Participants unanimously expressed great dissatisfaction with some of the behaviors and practices of HCW at the facilities, which they termed as disrespectful and a total disregard for the patients. These practices and behaviors, reportedly, made individuals not want to go to the clinics.

*“It is a form of stigma, you find even the way the person treats you inside his heart, treats you with disrespect like you are not important
(Female 18-30 years).*

“I see in your actions even as you walk especially women..... even the way she talks to you in a rude way, you get frustrated”
(Male 31-50 years).

“ he will look at your physical appearance and put your card aside and ask his colleague whether tea is ready”
(Female 18-30 years)

The most disliked behavior and practice cited across all FGDs included the manner in which adherence counselling was done and the practice of making patients who had defaulted sign commitment agreements to adhere to clinic attendance and medication regimen as prescribed.

“They wanted to cancel treatment because they said we had to commit ourselves, she committed by signing and may be a person forgets to take medicine because they are sick”
(Male 31-50 years);

The participants in the FGDs reported that HCWs would ask for tea to be brought to them and go on a tea break while patients waited. They also reported that patients’ files took too long to be retrieved, prolonging the waiting time.

“There are those who ask for permission from their place of work for a short time to pick drugs and only to find staff chatting or taking tea and they tell you they did not send you to get HIV.....”
(Male 31-50 years).

*“Imagine you are standing there, he will pick tea, come and start taking it.
Your card is there,
you tell him you are feeling bad,
try to plead with him if he can allow you to see the doctor,
and he asks you if he sent you....”*
(Female 18-30 years).

The participants expressed dissatisfaction on



the use of unprofessional language by health workers as they serve patients.

*“..... they asked me whether
I was there to train them
on their work and they do not care who I am”
(Female 18-30 years).
“....there is a tendency of bad mouthing
where one is asked by the health care provider
if they were taken there by them or
they went and caught the virus on their own”
(Male 31-50 years).*

Participants also reported dislike of the required intra-facility movement for their care having to go from station to station within the facility for various reasons, they termed this as being tossed around and “eventually you are turned away”, meaning that ART initiation does not occur on the same day.

*“They talk so much about treatment and
when you go the facility,
you are tossed around and turned down”
(Female 18-30 years).*

The participants reported lack of trust of HCW and attributed death of a fellow villager to having been killed by the HCWs due to their poor attitudes towards the PLHIV.

*“.....we managed to admit the patient and
after four days he died.
At the back of my mind I knew they had killed him
because they treated us badly”
(Female 18-30 Years).*

DISCUSSION

This paper explored the psychosocial experiences and issues that determine how the community and PLHIV in this informal settlement perceive the services that PLHIVs receive as they seek HIV services. The perceptions may influence their attitude, either encouraging or discouraging the PLHIV from seeking and continuing with ART.

Three major themes emerged in this study; knowledge, benefits and choice of ART facility; timing from testing to HAART uptake and behaviors and communication of HCWs toward their patients.

The participants had very good knowledge of the health facilities that offer HIV care and treatment within and around the informal settlement. Incentives offered by some facilities served as motivators to the choice of facility to enroll in for treatment.

Facilities that offered incentives including food, free hospitalization support, ambulance services and soap were preferred to the rest of facilities.

A study in India showed that providing voucher incentives redeemable for food and household goods improved linkage and retention in care but did not have an effect on viral suppression [18].

This would suggest that participants were retained in the facility because of what they received but may not have had good adherence to (ARVs).

Hence poor viral outcomes. Additionally, a study in Australia, found that even with the provision of incentives, the treatment uptake remained suboptimal among those infected with HIV as they valued relationships more than incentives.

The study suggested that treatment must be tailored to fit the logistical, social, and cultural context of everyday life and issues of sustainability must be looked at when considering incentives as a package of care [19].

In this study a minority of participants did not encourage the provision of incentives to respondents in this informal settlement.

They reported that Respondents became more concerned about incentives offered than treatment.

Before the adoption and launch of the new ‘*test and treat*’. Treatment guidelines in Kenya's, common pathway for any participant consisted of testing for HIV and if infected, referral and linkage to care. Assessment of ART eligibility including WHO staging and CD4 measurement, and treatment preparation which in many cases required several visits to assess readiness.

This occurred without a clear understanding of the rationale for these processes by clients. This could be because either the clients are not given an explanation about pre- ART sessions, or they do not understand nor



appreciate the process; thus causing them frustration which leads to non-return to the facility. participants in this informal settlement expect to be started on ARVs on the same day that they attend a treatment facility. Losses occurring prior to ART have been observed elsewhere too [12].

The expectation by clients of same day initiation of ARVs may be a facilitator to the implementation of Kenyan new HIV treatment guidelines recently rolled out recommending immediate initiation of ART for clients testing HIV positive (20).

Perceptions about HCWs' behavior

The major challenges for respondents attending ART clinics in resource-constrained countries documented include costs, distance from where participants live, taking time off from work, waiting time for services at the facility and inflexible clinic hours for the working population [21, 22, 23].

However, in this study the major barriers faced by the community and respondents as expressed by the them were perceptions about health workers actions, behaviors, communication and interpersonal relations with patients which were viewed as demeaning and not client-centered and these hindered service uptake and retention in care.

Clearly, participants perceived lack of professional etiquette and preparedness by the HCWs. Most participants felt a sense of not being valued and being looked down upon.

They would be kept waiting while HCWs engaged in private conversations, spent time taking tea and used derogatory and unprofessional statements like "*we did not send you to get HIV*". PLHIV's self-esteem may already be eroded and low due to their illness and they require warmth and empathy from service providers [11].

Of most concern was the intensive adherence counseling offered to those on ART, which typically requires a non-adherent participant to show commitment to treatment often by signing a document which is then filed in the patients' records.

A study in Zambia found that this was a major

reason for participants to give up ART by not returning to the clinic [24].

Although clients agree to sign undertakings to adhere to clinic attendance as appointed, an observational cohort study in Kenya showed that compliance with the contract signed is only 40% and poor adherence accompanied with poor viral suppression persisted [25].

The HIV positive participants perceived or real changed physical appearance with accompanying psychosocial stress make them have low self-esteem, become very sensitive and be quick at picking cues and perceiving HCW actions negatively, feeling stigmatized and discriminated against [3, 4, 5].

Patients easily give up attending their routine care due to perceived poor attitudes of HCW towards them [12].

All the above perceptions may contribute to defaulting treatment. A review by Nyblade et al suggests that stigmatizing and discriminatory tendencies are found among health workers because of lack of awareness of what stigma looks like and the association of HIV to immoral behavior [26].

In a study in Egypt, the health workers clearly said that PLHIVs should be ashamed of themselves [27], this confirms stigma.

Adherence counseling is very important and should continue, but the manner in which it is conducted should be reviewed to make it more supportive rather than punitive and degrading. The use of rough or unkind language by HCWs has been shown to be an important reason for patients to stop HIV treatment [28, 29].

Results

A patient centered approach to care [30] is a core element in achieving quality care for any individual and it is necessary to constantly review providers' competencies and interpersonal skills. Patients who are satisfied with their care are more likely to adhere to treatment and have better health outcomes.

The five conceptual dimensions of a patient centered approach namely: biopsychosocial perspective; 'patient-as-person'; sharing power and responsibility;



therapeutic alliance; and 'doctor-as-person' [31, 32] should form the basis of staff development to promote patient satisfaction and retention in care even as differentiated models of care are being considered.

In addition to the patients' service charter that is a requirement in all health facilities in Kenya, programs should consider developing a patient / provider interaction code that reflects patients' psychosocial circumstances.

Suggestion boxes do exist in most health facilities in the country but these are rarely used, neither has their effectiveness been evaluated. Eliciting participants feedback on the care they receive by this and other means throughout their continuum of care should be strengthened and the process structured so that comments are reviewed on a regular basis.

The major limitation of this study was failure to separate the PLHIVs from the non-infected persons so that responses can be attributed properly to specific categories.. However, this was deliberate and we presume that this promoted free discussions and expressions without bias and elicited the perceptions of the community at large.

We also acknowledge that perceptions may not reflect a true cause and effect for why PLHIV may not either access, uptake or be retained in ART services. Additionally the perceptions of the treatment supporters may not be the same as the patients.

Future work should decipher these two aspects to get the actual influences on treatment uptake and retention as well as assess the impact of treatment supporters on ART retention.

The other limitation is the sampling method of convenience sampling which by its nature would pick out the outgoing members of the community thus the results may not be generalizable.

Another limitation is that in two of the focus groups, there were more men than women and this made the women not speak out as much as in other groups. Where it was observed that women spoke less, attempts were made to mitigate this phenomenon by the moderator deliberately prompting all participants equally to share their views.

However, our study has generated new insights about patient-provider interactions that may hinder uptake and retention on ART.

Conclusions

Individuals who were diagnosed with HIV during HBTC and referred to care and treatment facilities in Kibera informal settlement generally accessed treatment facilities. They however did not do so immediately upon referral as most of them first went to confirm their diagnosis of HIV infection, while others waited until they became sick before going to enroll for treatment.

The availability of many health facilities is an enabler to seeking HIV treatment; however, the community members' satisfaction with services appears to be influenced by whether or not they felt listened to and treated with kindness and dignity. These factors may have an impact on their health seeking behavior and retention on treatment.

The informal settlements are characterized by very low socio-economic conditions and harsh environmental circumstances that may influence the residents' estimation of low self-worth; this is further eroded by poor interpersonal relations with HCWs.

Providers should therefore be sensitive to the perceptions of the community they serve and strive to improve the patient-provider relations as much as possible. Institutional policy to mitigate stigma and discrimination tendencies should be developed in a participatory manner, communicated and monitored [33] to help staff overcome stigmatizing tendencies towards patients.

Innovative patient-centered adherence counseling models may be useful as a component in HIV care and treatment. A well-documented management plan shared with the client would be helpful in enabling understanding of the treatment plan and promote adherence and retention.

The rights-based approach in care for PLHIV may address many of the issues identified in this research including respondents' participation in the study design and implementation of programs. Informed decision making about their health and lives.



Protection from harm. Opportunities to seek redress and accountability for perceived abuses [29].

List of Abbreviations

ART – Antiretroviral Therapy
ARV - Antiretroviral drugs
CHW - Community health worker
DGHT- Division of Global HIV/AIDS and Tuberculosis
FGDs – Focus Group Discussions
HBTC– Home-Based Testing and Counselling
HCW – Health care worker
HIV – Human Immunodeficiency Virus
HTC – HIV Testing and Counseling
NASCOP – National AIDS and Sexually Transmitted

Infections Control Program

NGO – Non-Governmental organization
PEPFAR- United States Presidents Emergency Plan for AIDS Relief
PLHIV – People living with HIV
WHO World Health Organization

What is new?

- The form and structure of adherence counseling as it is done currently is detested and not appreciated by clients.
- Psychosocial issues affect retention in ART just as much as logistical issues and should therefore be of greatest concern to provider.
- The value of patient centered approaches that promote satisfaction are revisited. This paper brings out their importance in facilities that offer long-term care such as ART services. Techniques that promote these approaches should be included in continuing medical education sessions in facilities that offer ART.
- Incentives promote access and attendance to clinics but not necessarily adherence to ART as clients in this study reported also being enrolled in another facility that offer incentives.

Competing interests

The authors declare that they have no competing interests.

Authors' Contribution

RPO conceived, designed and moderated the FGDs, supervised the transcription of FGDs and did the analysis of the transcripts. Interpreted data, wrote the manuscript, submitted and gave approval for publication.

Hence, is responsible for any queries arising thereof. DM supervised the transcription of the FGDs and helped in the interpretation of the themes for the manuscript. MK, ZN, and JO read, gave comments and made valuable inputs on the manuscript.

Authors' information.

The lead author RPO (MPH) is a HIV prevention specialist working at CDC Kenya with primary responsibility and focal person for HIV testing services and technical lead for the HBTC services. She was the activity manager for the cooperative agreement under which this work was carried out and was responsible for the sound programmatic aspects, offering technical direction and support, overall management for the implementation of the project. Acknowledgements

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Disclaimer

The findings and conclusions in this paper are those of the authors and do not necessarily represent the official position of the CDC and the Government of Kenya.



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