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Doubts, denial and divine intervention: Understanding delayed attendance and poor retention rates at a HIV treatment programme in rural Tanzania

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Abstract

Irregular or delayed attendance at HIV treatment clinics among HIV-positive individuals can have negative implications for clinical outcomes and may ultimately undermine the effectiveness of national treatment programmes. This study explores factors influencing attendance at HIV clinic appointments among patients in a rural ward in north-west Tanzania. 42 in-depth interviews and 4 focus group discussions were conducted with HIV-infected persons who had been referred to a nearby ART clinic, and in-depth interviews were undertaken with 11 healthcare workers involved in diagnosis, referral and care of HIV-positive patients. The Health Belief Model was applied to explore the role of health-related beliefs and the perceived barriers and benefits associated with regular clinic attendance.

Perceived susceptibility to HIV-related illnesses emerged as an important factor influencing clinic attendance, and was often manifest through expressions of acceptance or denial of HIV status and knowledge of HIV disease progression. Denial of HIV status was often associated with using alternative healers, and could occur prior to, during, or after starting ART. Perceptions of illness severity also influenced HIV clinic attendance, and often evolved in relation to changes in physical symptoms. Barriers to clinic attendance frequently included health systems factors, while physical and social benefits encouraged regular clinic attendance. Self-confidence in being able to sustain clinic attendance was often determined by patients' expectations or experiences of family support.

These findings suggest that multi-faceted interventions are required to promote regular HIV clinic attendance, including on-going education, counselling and support in both clinic and community settings. These interventions also need to recognise the evolving needs of patients that accompany changes in physical health, and should address local beliefs around HIV

aetiology. Decentralisation of HIV services to rural communities should be considered as a priority to redress the balance between perceived barriers to, and benefits of accessing HIV treatment programmes.

For Peer Review Only

Introduction

With an increasing number of patients enrolled in antiretroviral therapy (ART) programmes in Africa, attention has recently focused on the frequency of missed clinic appointments and default from treatment programmes (Rosen, Fox, & Gill, 2007). Regular attendance at HIV treatment clinics is essential for monitoring disease progression, providing prophylactic drugs to reduce the risks of opportunistic infections, ensuring timely ART initiation, and optimising long-term benefits of treatment.

Despite the need for interventions to promote patient retention, few qualitative studies have focused on factors influencing timely, regular and sustained attendance at HIV clinics. This study explores determinants of access to a HIV treatment clinic among recently diagnosed HIV-positive patients in Tanzania.

Methods

Study setting

The Kisesa cohort study in rural Tanzania has monitored the HIV epidemic through serological and demographic surveillance activities since 1994 (Mwita et al., 2007). The ward includes six villages and around 28,000 residents. HIV prevalence among adults > 15 years of age during the 2004 serological surveillance round was ~8% (Mwita et al., 2007), and approximately 30% (250/810) of HIV-positive adults were estimated to need ART during the first year of the national treatment programme in 2005 (Wringe, 2007).

VCT services are available in the ward's health centre, with referrals provided to a government-run, hospital-based HIV treatment clinic, located 20km away in Mwanza City. Referred patients are given a transportation allowance and a local home-based care (HBC) organisation provides support services.

Two-part referral forms are used to monitor delays in registration at the HIV clinic, and are linked to HIV clinic data by recording unique patient identifiers on both referral slips and patient medical records. By March 2007, two years after initiating the referral system, 137 adults had been referred to the HIV clinic of whom 22% (30) had not registered within 6 months of referral. Among 107 adults who registered, 36% were no longer attending at 6 months of follow-up.

Data collection

42 in-depth interviews (IDI) and 4 sex- and residence-specific focus group discussions (FGDs) were conducted with referred HIV-positive patients to explore factors influencing HIV clinic attendance. IDIs were also conducted with 11 healthcare workers (HIV clinic staff, HBC workers and VCT counsellors) involved in the diagnosis, referral or care of the ward's HIV patients, to elicit their perceptions of factors influencing patients' clinic attendance.

Sampling strategy

The sampling frame included Kisesa residents who were referred to the HIV clinic, and were members of the local HBC organisation (to facilitate delivery of study invitations). Delays in attending clinic appointments were calculated by comparing scheduled versus actual appointment attendance from patient records. Participants were then purposively selected to include those with regular and irregular attendance patterns over different time-periods (figure 1). Among the 45 selected participants, 36% (16) were men (compared to 33% (22/66) in the sampling frame), and 24% (11/45) lived in remote villages (compared to 23% (15/66) in the sampling frame).

The FGDs were open to diagnosed HIV-positive persons, with invitations made via the local club for persons living with HIV/AIDS (PLHA) and the VCT counsellors.

Ethical clearance

Ethical clearance for the study was obtained from the Medical Research Coordinating Committee (Tanzania) and the London School of Hygiene and Tropical Medicine (UK).

Data analysis

The FGDs and IDIs were recorded with prior consent from participants and then transcribed, translated into English and entered into NVIVO7 for analysis. A coding scheme was derived from the data by assigning codes to major concepts mentioned by the participants in relation to clinic attendance, which were then grouped in accordance with the major elements of the Health Belief Model (HBM), as described below. Hypothesis generation and testing took place throughout the analysis. A comparison of the major themes emerging from the analysis was carried out with a second researcher who independently coded the data.

The Health Belief Model

The HBM was applied to conceptualise the individual and social determinants of access to health services among HIV-infected individuals, and has previously been used to describe clinic attendance, as well as HIV-related behaviours among various populations including those in African settings (Hounton, Carabin, & Henderson, 2005; Mkanta & Uphold, 2006). The basic structure of the model is derived from psychological theories suggesting that health-seeking behaviours are determined at the individual-level by a desire to avoid illness, and a belief that a particular course of action will prevent or relieve illness (Janz & Becker, 1984). There are several dimensions to these concepts in relation to attendance at HIV clinics, including perceived susceptibility to HIV-related illnesses, perceived severity of HIV infection, perceived benefits of clinic attendance, perceived or real barriers to clinic attendance, and perceived self-efficacy in seeking treatment. Table 1 defines these concepts

and summarises the way they find expression in the context of HIV clinic attendance in this setting.

Notation

Quotations from patients are denoted by sex and remote or roadside village of residence (Re or Ro). Quotations from HCW include a 3-letter abbreviation to identify whether they work at the *HIV* clinic, *VCT* clinic, or the *HBC* programme.

Results

Perceived susceptibility to HIV illnesses

Perceived susceptibility to HIV-related illnesses emerged as an important determinant of clinic attendance, and was manifest through expressions of acceptance or denial of HIV status and knowledge of disease progression. Doubt over HIV status was sometimes associated with having no symptoms consistent with advanced HIV infection, as one HBC volunteer reported:

Another sees that his health is good.....I mean he says that I have no disease. They [doctors] are lying. They didn't check [my HIV status] well. [HCW-HBC-7]

Perceptions of susceptibility were also shaped by local concepts of AIDS aetiology. In particular, local beliefs that HIV-like illnesses were attributable to witchcraft and could be cured often had a detrimental effect on clinic attendance. Furthermore, there were reports of default from the HIV clinic if patients concurrently consulted traditional healers:

You will discover that you have this disease. Then you go somewhere else to a traditional healer. You will get that false belief from the traditional healer because he will tell you that you have been bewitched by so-and-so... Then you quit following up the drugs. [Re-M-FGD]

In other cases, denial of HIV status was reflected in claims of being cured by God. One ART patient who stopped attending the clinic for several months explained how he attributed his "cure" to his religious faith:

And till now you know, I have even disturbed the minds of these counsellors. They are disturbed so much, 'why, it seems this person doesn't use medicines, what's wrong?' When they ask me, I tell them that 'I am saved, God has healed me.' [Re-M-12]

Persistent denial of HIV status often represented a response to feeling overwhelmed by the life-long requirements of clinic attendance, as the patient who reported being cured by God later explained during his interview:

At first they were giving me fear and worry that the medicines are for the whole of my life. That's why I found myself having so much faith that so God can make use these medicines...

It quickly comes to my mind that 'daah, perhaps I forgot them.' ... that fear, it's that you are told that if you don't use these medicines your former condition will return, so I worry ... but now I stick more to God.. he will take care of me. [Re-M-12]

Perceived HIV severity

For most patients, perceived severity of HIV was determined by the presence of physical symptoms, with severe illness onset often prompting clinic attendance. Furthermore, some patients who perceived their illness to be serious overcame initial obstacles to clinic attendance, including embarrassment at being seen:

Once you feel that your health is not pleasing, you will stop being shy. Why should I fear someone? Do you want me to die? So you stop being shy. Why should I fear a human being when God is seeing me? [Ro-F-FGD]

Conversely, some patients whose health improved after initiating prophylactic treatment to reduce the risk of opportunistic infections or ART would miss subsequent appointments until their condition deteriorated again, while others decided to defer ART initiation in the absence of symptoms, despite having a very low CD4 count.

There are many examples of patients who don't want to start treatment until they feel very, very ill. One man came just recently to the clinic, with a CD4 of 130...but said that he didn't feel ready to start taking ART yet.. ..he thought he was just fine to wait... since anyway, for now, he is still feeling OK. [HCW-HIV-11]

Benefits of using HIV clinic services

Anticipated or experienced benefits of attending the HIV clinic often promoted regular clinic attendance. Improvements in physical well-being were frequently cited and were associated with returning to daily activities which many patients had suspended, enabling some to regain feelings of independence:

I went to follow up my health to get treatment so that I could continue doing my activities just as I was doing before. So that I don't live by depending on someone, because it will be worse to depend on someone. [Re-M-51]

For some participants, continuously monitoring their disease progression, or having access to regular, free medical advice were also perceived as important benefits of maintaining clinic attendance:

I want to go to clinic after short intervals... it's when I can see how I am getting on. sometimes I have got so many thoughts... but if I go to clinic and check even the doctors will just tell me 'Do this.' They will give me advice. [Re-F-24]

Positive social outcomes such as the ability to spend time with family and friends, or raise young children were also perceived as important benefits of improved health:

I decided to come and test [my CD4] because of how I used to see my health. I used to think that I was healthy but I was found with a disease. So I had to encourage myself.. one day perhaps I too will leave this world so let me encourage myself and maintain my children because they are still young. [Ro-F-50]

Conversely, a lack of perceived benefits, such as reported side-effects, or beliefs that ART and prophylactic drugs were ineffective or would accelerate disease progression were relatively common, and could negatively influence clinic attendance, as could a lack of physical improvement following treatment initiation:

We hear just many things...Others are saying that you can use these drugs and after a long period they will masticate the intestines and as a result they will rot... then you will die before your days, you will die early. [Re-F-FGD].

Those drugs for opportunistic infections, you continue swallowing them but you don't feel any better. It is better I quit using them...and just stay at home. [Re-F-FGD].

Perceived barriers to using HIV clinic services

Health systems factors were commonly reported practical barriers to regular clinic attendance. The distance to the clinic and long journey times represented a particular challenge for patients who were unwell, or unfamiliar with the hospital environment, and could explain preferences for traditional healers:

If he gets these problems even if you tell him to go to Bugando [hospital], others since birth they don't know Bugando. He/she hears that it's a very big building in town there...[So] they are attended by traditional healers. When he thinks of going to Bugando it's far! [Ro-M-01]

Once at the HIV clinic, some patients reported dissatisfaction with the services, particularly long waiting times to be seen by clinic staff which prevented them from undertaking their usual activities

The problem emerges when you stay there for three hours without being attended... you find even someone quitting using the drugs. He will say that, after all...they continue ignoring me, I have been here for five hours, without being attended. You actually find many people...abdicating due to delays of treatment. [Ro-M-19]

Some participants also referred to psychological costs associated with attending the clinic. In particular, community-wide stigmatisation of HIV was often manifest in the fear of being identified as a HIV-positive patient through attending the clinic:

The other obstacle is fear. She may be fearing that, right now I am infected, when I go there everybody will see me as someone who has been affected. I just hide myself in the house. She no longer has that problem of following up She has only to stay at home. [Ro-F-FGD]

Anticipated or experienced conflicts with family members were also common, with some women reporting accusations of promiscuity when they were absent from home at the clinic. One participant explained how her mother-in-law's malicious rumours about her absence from the house delayed her attending her referral appointment:

Because of the problems at home there, there were so many problems [with] my mother-in-law.So I feared to leave home, because once I leave home she says I am going to the houses of my lovers. [Ro-F-50].

Although there were reports of patients attempting to overcome these barriers through non-disclosure of their HIV status, these pressures could result in patients defaulting from the treatment programme in the long-term:

When she goes to the clinic she uses her own ways ...and she gets those drugs, and when she brings them at home, she has to take them secretly. Now she starts telling herself, 'there is a day when I will be discovered here'. Now when she regains her health, somehow she thinks that she is cured. She decides to quit taking the drugs. [Ro-F-FGD].

Self-efficacy

A perceived ability to take action to attend the clinic also emerged as an important factor that could promote or hinder regular uptake of scheduled appointments. Several patients referred to this self-efficacy when describing how they had established a strong sense of autonomy in their treatment-seeking decisions:

Because I thought that really this is my health and nobody else's. So even if I involve another person, you know people differ, and he/she misleads you. He/she can say ...you will get this and this side effects. So I decided it just myself, no matter what I will get there because I go to seek my life. [Ro-F-50]

When I returned home I separated with my husband, that is the problem I had. But I didn't care about all that, I felt that it was better I cared about my health. [Re-F-20]

However, in other cases, family pressures represented the greatest challenge to achieving self-efficacy in attending clinic appointments. Family preferences for the illness to be treated by traditional healers or church leaders resulted in some patients failing to negotiate clinic attendance, despite their own desire to use biomedical services.

Sometimes [the patient] wants to go and check CD4 but you find that the family takes him/her to traditional healers. Some families ...they say that these [healthcare workers] just deceive you, you must be bewitched. [HCW-HBC-7]

Discussion

This study explored reasons for delayed attendance at HIV clinic appointments in rural Tanzania, and applied the HBM to highlight the presence of multiple and inter-related factors that influence care-seeking from biomedical services. These findings suggest that the factors

influencing HIV clinic attendance often varied among the same individuals over time, according to current experience of illness, and the overall balance between the barriers and benefits of appointment attendance.

The perceived benefits of HIV clinic attendance in this setting often related to the consequences of improved health, suggesting that VCT counsellors have an important role to play by emphasising potential positive outcomes of clinic attendance and addressing concerns that hinder the uptake of appointments. In the longer term, decentralisation of HIV treatment services to local health centres is likely to change the balance of perceived barriers and benefits of clinic attendance and may help to promote retention in the programme among patients who experience improved physical health.

These findings also suggest that in order to promote effective care-seeking practices, HIV information campaigns need to highlight benefits of an early diagnosis and sustained programme enrolment. Furthermore, additional counselling is needed for patients whose physical health does not immediately improve, particularly since mortality among ART patients may send negative signals to the community about the treatment programme.

These results also serve as a reminder of the persistent nature of HIV-related stigma towards infected persons in this setting, and should prompt greater efforts to promote mobilisation activities to combat its manifestations at a family and community level. HBC groups or PLHA networks, which are already established in many communities, may represent an appropriate channel for providing social support, and may also prove useful for promoting patients' self-efficacy in treatment-seeking.

Preferences for traditional healers over biomedical services and disease causation beliefs were also found to hinder regular clinic attendance in this setting. These preferences may be explained by the costs of accessing the services, familiarity with their methods, perceptions of treatment efficacy, and lower levels of stigma associated with using their services (Fairfield, Eisenberg, Davis, Libman, & Phillips, 1998; King & Homsy, 1997; Plummer et al., 2006). Future research should involve traditional healers to explore the potential for their inclusion in promoting successful access to HIV services, and should also explore the origins of HIV causation beliefs to address knowledge gaps in HIV aetiology that negatively impact adherence to clinic schedules.

These findings need to be considered in the context of various limitations, including possibility of social desirability bias in participants' responses. However, the use of FGDs in addition to IDIs enabled participants to discuss issues that could impact clinic attendance, without implying their own personal experience, as well as providing an opportunity to triangulate information from different sources. Refusal to participate may also represent a source of bias. However, only 3/45 patients (2 women and 1 man) declined their IDI invitation, which is likely to be because they had already had contact with HIV services having attended VCT.

In conclusion, these findings suggest that multi-faceted interventions are required to promote regular HIV clinic attendance, including on-going education, counselling and support in both clinic and community settings. These interventions should also recognise the evolving needs of patients that accompany changes in physical health, and should address local beliefs around HIV aetiology. Decentralisation of HIV services to rural communities should be considered as

a priority to redress the balance between perceived barriers to, and benefits of accessing HIV treatment programmes.

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Table 1: Concepts and definitions used in the Health Belief Model in relation to HIV clinic attendance

Concept	Definition	Expressions of the concept
Perceived susceptibility	Assessments made by a HIV-positive patient of the likelihood of succumbing to HIV-related illnesses, including death	Denial of HIV status; Understanding of disease progression; Beliefs around HIV causation, including belief in a cure for HIV
Perceived severity	HIV-positive patient's opinion of how serious HIV infection and its consequences are.	Influence of poor physical health on initiating clinic attendance; Consequences of improvements in health on clinic attendance
Perceived benefits	Anticipated or experienced positive outcomes of attendance at HIV treatment clinics;	Improvements in health; Ability to return to work; Ability to care for children; Social acceptance when well
Perceived barriers	An individual's assessment of the tangible and psychological costs of attending HIV treatment clinics	Inability to overcome health systems barriers (queues, travel to clinic etc); Psychological costs include impact of discrimination or segregation by family or community
Self-efficacy	An individual's confidence in their ability to regularly attend the HIV clinic	Often determined by ability to live independently; Ability to overcome family influences on treatment-seeking decisions

Figure 1: Invitation and participation among eligible HIV-positive adults, by number of missed appointments and referral period.

