The perspectives of users of antiretroviral therapy on structural barriers to adherence in South Africa

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Abstract

Background: The effectiveness of antiretroviral therapy (ART) and the importance of adherence to treatment regimens are widely known. Yet, suboptimal adherence to ART and retention in care of patients still persists and, by many accounts, is fairly widespread. The aim of this study was to identify the structural barriers that influenced adherence among patients who were enrolled in the national ART programme in South Africa.

Method: In this qualitative study, semi-structured interviews were conducted with a sample of 10 patients receiving ART at a public hospital in South Africa.

Results: The results of the interviews were categorised according to poverty-related, institution-related and social barriers to clinic attendance and pill-taking, which collectively formed the structural barriers to adherence. The chief structural barriers to clinic attendance were time away from work, transport expenses, long waiting times and negative experiences with clinic staff. The chief barriers to pill-taking were food insecurity, stigma and discrimination.

Conclusion: The barriers to adherence are discussed. Attention is called to the extraindividual factors that influenced ART adherence. We conclude that contextual factors, such as a healthcare-enabling environment, might play an important role in influencing healthcare-promoting behaviour among patients.

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Introduction

South Africa has the fastest-growing human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) pandemic in sub-Saharan Africa. There is an average prevalence rate of 10.8% among the general population.[1] Despite the availability for several years of antiretroviral therapy (ART), commencement of the national dissemination of antiretroviral treatment to South African patients has been very recent. While the national distribution is an important public healthcare measure in South Africa, the mere availability of treatment is insufficient for patients to make gains in terms of their health status. Retention of patients in care and treatment adherence are important dimensions of therapeutic success.

Poor adherence to ART is highly predictive of viral load and drug resistance.[2] Therefore, it might have serious implications for the control of symptoms, recovery time, quality of life and mortality among HIV-infected persons. Moreover, poor adherence might lead to the development of drug-resistant strains of HIV, resulting in resistance to treatment and the need for more expensive second-line medication.[3] Considerable wastage is likely when resources are directed at medical consultations, purchase of medication, transport to appointments and other aspects surrounding medical care, if adherence to the treatment remains low. For these reasons, retention of patients in care and adherence to ART are of considerable importance. A high level of adherence to treatment is required for optimal effectiveness and the prevention of drug-resistant strains of HIV.[4]

According to Hardon et al,[5] pooled data from samples of patients in several African countries indicated that 77% achieved adequate levels of adherence. Yet, much of these data were collected in experimental settings in which patients were required to meet specific criteria before enrolling, such as disclosure of their HIV status to at least one other individual. Studies conducted in resource-constrained contexts suggestive of high adherence levels mainly relied on self-reported adherence, which was often unreliable, tracked small numbers of patients over short periods of time, or were conducted cross-sectionally so that adherence over time could not be assessed.[6] In their review of ART programmes in several African countries, these authors showed that suboptimal rates of adherence are common, and that adherence to care often declines significantly over time, prompting these authors to call for urgent research into the responsible factors for this phenomenon. A systematic review of patient retention in ART programmes in sub-Saharan Africa showed that approximately 60% of patients had remained in care after two years of treatment.[7] In this review of 32 studies that reported on a total of over 74 000 patients in 13 countries, loss to follow-up accounted for most attrition, leading the authors to call for better patient-tracing procedures and a better understanding of loss to follow-up and earlier initiation of ART, as ways to improve retention of patients in care.

Individual, psychological and behavioural factors have been identified as barriers to adherence.[8] These include treatment side-effects and poor health literacy,[9] lack of social support,[10] poor mental health,[11] substance abuse,[12] stigma and discrimination,[13] and treatment efficacy.[14] Less attention has been given to structural barriers to adherence. These are the political, economic and environmental factors that reduce the likelihood of access to health care and that negatively influence pill-taking behaviour.[15]

Structural barriers can be divided into three categories, namely poverty-related barriers, institution-related barriers and political and cultural barriers. Poverty-related barriers include the costs and circumstances associated with travelling to the clinic,[5] food insecurity,[5] loss of wages,[16] disincentives associated with disability grants[17] and lack of social support.[18] Institution-related barriers include overburdened healthcare facilities,[19] inadequate access to mental healthcare facilities[20] and insufficient numbers of adherence counsellors.[21] Political and cultural barriers include political controversies such as AIDS denialism and disputes about the effects of ART,[17] migrant labour,[18] traditional convictions,[19] health illiteracy[9] and stigma.[10] The present qualitative study sought to document South African ART users' perspectives on the chief structural barriers to adherence.

Method

Participants

All participants were HIV positive, were enrolled in the national ART programme and received their medication from a hospital in the Western Cape region of South Africa. The final sample consisted of 10 patients; seven men and three women, aged 22-37. The patients were all black South Africans, who were either unemployed or employed part-time in the informal sector. All reported that they were poor. They were recruited via a nongovernmental organisation (NGO) that provides psychosocial support services to ART users. The NGO identified that these patients had difficulty with adherence. Patient advocates, who were laypersons who assisted patients with adherence, also helped with sample recruitment.

Ethics procedures

Ethics approval was obtained from the Health Research Ethics Committee of Stellenbosch University and the Western Cape Department of Health. The names of the respondents were changed to ensure their anonymity.

Interview procedure

Semi-structured interviews were conducted with participants, the purpose of which was to obtain a rich narrative that would be suitable for qualitative data analyses. A standard interview schedule was used that contained open-ended questions, as well as follow-up probes. These interviews were conducted by the lead researcher who had considerable experience in qualitative interviewing. The interviews proceeded until saturation point was reached. The interviews were conducted in a private room under confidential conditions. On completion of the interview procedure, participants received a grocery voucher as a token of appreciation for their time.

Data analysis

The interviews were recorded, transcribed and imported into Atlas.ti 4.2®, a computer programme that assists researchers with the analysis and interpretation of large quantities of textual information. The programme enables researchers to select, code, annotate and compare important segments of the text.

Results

Table I presents a summary of the study findings. These are divided into poverty-related barriers, institution-related barriers and social barriers.

Poverty-related barriers to clinic attendance

Time away from work

Patients reported that they were often absent from work for a whole day, because of the large number of patients and long waiting times at clinics.

Table I: Key barriers as they related to adherence to care and pill-taking

Adherence to care	Adherence to pill-taking
Poverty-related barriers	
Time away from work	Food insecurity
Travel expenses and distance	
Institution-related barriers	
Long waiting times	
Negative experiences with clinic staff	
Access to substance abuse treatment programmes	
Social barriers	
	Stigma and discrimination

A female participant, Laura, explained:

"*...when I was still working and I had to come to the clinic for my appointment, I had to ask for a day's leave in order to go to the clinic....*"

Patients reported that their absence from work often meant losing a day's wage, given their conditions of work. Such conditions often proved prohibitive for many patients when considered in the context of their living expenses. This resulted in their choice to go to work, rather than attend clinic appointments.

Travelling costs, distance and personal safety

Travel expenses and distance were major barriers to adherence. Participants indicated that they used public transport, particularly minibus taxis, which were expensive and in some cases not affordable.

Greg, a 39-year-old patient, said:

"*I'm stressed, especially in the mornings when I know it's my date to go to the hospital and I have no money. I have to see the doctor... then I have to walk, because there is no money and the taxi fee is ten rand, ten rand!*"

Another patient, Jane, reported that she had walked three hours to the hospital and had already terminated her treatment once. She stated:

"*I don't think I will be able to walk to the hospital anymore, because it is takes a lot of time walking to the hospital and it makes you very tired and it even makes you feel sick, because it is very hot.*"

The issue of risk to personal safety also emerged as an important factor. Patients reported that they often needed to walk to the clinic in the dark in order to arrive early in the morning. They were concerned about their personal safety, given the high rate of crime in the communities in which they lived.

Greg described his experience in the following manner:

"*I have to cross that busy road and then I have to walk past (name of township) and the people there are violent. I can only thank the Lord if I arrive safely at the hospital and from the hospital to my home.*"

The problems that patients experienced regarding transport, distance and security were disincentives to clinic attendance and thus to adequate HIV care.

Poverty-related barriers to pill-taking

Food insecurity

One of the main barriers to pill-taking identified by patients was food insecurity. Several patients indicated that they were often reluctant to take their medication on an empty stomach because of related side-effects, such as nausea, vomiting and dizziness.

Jennifer, a 32-year-old domestic worker, explained:

"*Sometimes there isn't anything to eat, there isn't always money, and sometimes there is no food in the house. You can't take your medication on an empty stomach because you have to have something to eat in order to take your medication.*"

It has been noted that ART might increase the patient's appetite and thus compensate for HIV-related weight loss.[5] Thus, maintaining a balanced diet, which is highly important for persons living with HIV, is made difficult due to living under conditions of poverty.

Institution-related barriers to clinic attendance

Long clinic waiting times

Patients reported that the long waiting times at clinics were a disincentive to clinic attendance. They reported that they often spent an entire day at the clinic in order to see the doctor or nurse for an appointment that lasted only a few minutes.

Edward, a 23-year-old man, indicated that attendance of clinic appointments was a problem for him, because of the long waiting hours. He said:

"*There are too many people there. Sometimes you wait three or four hours and then they just weigh you, then you have to wait again until they call you and then you can see the doctor and then you have to wait again.*"

Reports of this nature by the other participants were common.

Experiences with clinic staff

Patients reported that they found nursing staff to be unsympathetic and rude towards them. They reported that they felt unwelcome at the clinic and alienated from the healthcare system. This made them reluctant to attend the clinic.

Jennifer shared her experience:

"*… there are a lot of grumpy nurses. Their attitude isn't what it's supposed to be. A nurse once asked me why I was so late. Then I told her that I can't help it, I don't have transport, I walk to the hospital, I don't have money...then she said to me that I would just have to wait till she decides if she wants to help me.*"

Jennifer's quotation epitomised the experiences of several patients who felt that nursing staff members were indifferent to them, and sometimes even hostile.

Access to substance abuse treatment programmes

Several participants stated that substance abuse created problems for them.

Michelle, a 28-year-old patient, said that previously alcohol abuse used to impede her ability to adhere to ART. She said:

"*I also used to drink and then I would forget to take my medication, I didn't care*."

This experience was typical for other patients, who shared similar experiences. Michelle also spoke of the difficulty that she experienced in accessing treatment for her alcohol problem. This was reflected in others' experiences as well. While substance abuse was a psychosocial or medical matter for patients, the absence of available substance abuse treatment programmes was considered to be a structural barrier to ART adherence.

Social barriers to clinic attendance

HIV-related stigma

Participants indicated that stigma was a major problem in their families and the community, to the extent that they were reluctant to disclose their HIV-positive status to friends and family members.

Marcia, a 25-year-old patient, said:

"*The community is very small, it (gossip) goes around. It's not only the neighbours, it is everyone. If you start a small fire, then the whole field is burning, the way they go on*."

Another patient, Jessica, confirmed Marcia's experience of stigma: "*...and my friends, I haven't told them.... I don't tell them about it, because they will make it a problem. Tomorrow, the story will spread in every direction. That is why I will never tell them.*"

The stigmatised nature of HIV was closely associated with adherence, as patients were deprived of a significant source of social, instrumental and financial support that would facilitate clinic attendance and responsible pill-taking behaviour. Participants who had disclosed their status to family members or friends indicated they often reminded them to take their medication, assisted with transport costs and encouraged them to attend clinic appointments.

Participants said that they found it difficult to take their medication in front of family members who were unaware of their status. Some of the participants lived in overcrowded conditions with limited privacy due to poverty. This made it difficult for them to store and consume their medication without family members noticing.

James, a 20-year-old participant, described his living conditions in the following manner:

"*At the moment there are five of us in the bungalow and it is a wooden structure. It is very small, and there is only a big bed in the room in the bungalow, and all of us sleep on the bed*."

James went on to describe how he needed to hide the fact that he was receiving ART, to the extent that he sometimes did not take his medicine if he thought that someone might see him.

The combination of poverty-related barriers, institution-related barriers and social barriers proved challenging for the patients who participated in the study and accessed their treatment from the public healthcare system.

Discussion

The study sought to identify the chief structural barriers to adherence from the perspective of patients receiving ART. Overwhelming data on HIV incidence and prevalence in sub-Saharan Africa indicate that the disease is more common among the poor. Thus, in addition to the disproportionate distribution of the disease among economically impoverished persons, adherence is also made more difficult by living in poverty.

The data that emerged in the context of the research indicated that structural factors affected adherence at two levels. One was clinic attendance, which can be referred to as adherence to care. The other was actual pill-taking behaviour, which can be referred to as medication adherence. These two levels of adherence relate to each other and are inseparable.

In the context of widespread unemployment in South Africa, long waiting times create reluctance on the part of patients to take time off work to attend clinic appointments. In situations in which unskilled and semi-skilled seasonal and contract work, rather than permanent employment is common, the likelihood of retaining constant employment is tenuous at best. This creates a disincentive to attend appointments, especially when this requires the commitment of several hours that might be spent working and earning money instead. In addition, patients who are reluctant to disclose their HIV-positive status and who decide not to indicate their need for medical treatment to their employers, don't benefit from sick benefits, including time off work to attend appointments.

The issue of patients' physical safety as members of the general public also related to living under impoverished conditions. Income inequality is among the highest in the world in South Africa.[22] Poor South Africans bear a differential burden of social problems, one of which is violent crime. Most ART users who seek services from the public healthcare system live under impoverished conditions, which are simultaneously characterised by high levels of community violence. While seeking healthcare services, their physical safety is often uncertain. This creates an additional barrier to service utilisation.

Similarly, the level of efficiency of the South African healthcare system is a function of the two-tiered nature of health care in the country, namely private and public. Usually, patients receiving private health care have medical insurance, are employed and have a greater level of financial security than those who utilise the public healthcare system. Generally, those who make use of services in the public healthcare system do so because they are unable to afford private health care, which, without health insurance, is often prohibitively expensive.

In general, public health care in South Africa is often underfunded. Insufficient funds are directed at hiring nursing staff. Therefore, because of large patient numbers, many patients face the phenomenon of long waiting times, which serves as a disincentive to their clinic attendance. In the context of competing demands on their time, particularly work commitments, as discussed previously, and personal concerns such as child care needs and those of stigmatisation if services for AIDS-related health concerns are sought, many patients decide against clinic attendance. This results in potential defaulting.

Because of high patient numbers,[21] staff burnout is likely to occur. The experience of patients as they interact with overwhelmed staff is important to consider, as it is at this nexus that adherence and other health-related decision-making occurs. As positive relationships between healthcare staff and patients predict adherence levels,[23] in a situation in which such a positive relationship does not occur, adherence is likely to be suboptimal. Transport expenses and long waiting times, combined with negative experiences with nursing staff, many of whom experience burnout, create strong disincentives for clinic attendance.

HIV-related stigma is an ongoing feature of the AIDS pandemic worldwide. Many ART users prefer to seek services at clinics far from their homes to avoid being seen by members of their community. Transport expenses and difficulties constitute barriers to clinic attendance.[24] In addition to clinic attendance, stigma also affects pill-taking behaviour. Patients whose family members do not know of their HIV-positive status sometimes have to hide their medication and conceal their pill-taking behaviour so as not to arouse suspicion that they are living with HIV.[16] Together, these conditions create strong societal and social disincentives to adherent behaviour.

Strengths and limitations of the study

The use of qualitative research methods allowed for detailed descriptions of patients' perspectives on barriers to ART adherence. The small sample size, although appropriate for qualitative research, means that the research is not generalisable. Another limitation of the study was language, as interviews were conducted in Afrikaans or English, yet many patients were Xhosa-first-language speakers. Patient advocates acted as interpreters when necessary to minimise this limitation. Additional studies of this nature should be conducted in the home language of respondents so as to arrive at more nuanced perspectives of their experiences. This study identified key structural barriers to ART adherence from the perspective of patients. As such, it represents the way in which patients, as individuals, encounter and interact with the social and economic context in which they find themselves.

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