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Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers

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The present study examined the chief structural barriers to antiretroviral treatment (ART) adherence from the perspective of health care workers who provide treatment to patients living with HIV and AIDS in South Africa. The main barrier to adherence as identified by participants in the study was the stigma associated with living with HIV, and thus with receiving AIDS treatment. A second barrier was the fact that some patients willfully decide to forgo treatment so that they could retain state disability benefits associated with a low CD4 count. Other barriers included the lack of finances for transport to clinics and food insecurity, especially when medication needed to be taken with food. These barriers to ART adherence are conceptualized in terms of Bronfenbrenner’s Ecological Systems Theory.

Keywords: adherence; antiretroviral treatment; HIV/AIDS

Introduction

The prevalence of HIV in South Africa is among the highest in the world with the latest national prevalence estimate at 11% (Shisana et al., 2009). Presently, antiretroviral treatment (ART) coverage is 28% (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009) with intentions to increase this in coming years. ART requires high levels of adherence, i.e., taking the required dosage at the correct time, making sure that the dosage is ingested with the recommended foods, attending regular clinic appointments, and adhering to the general treatment regimen (Kalichman, Catz, & Ramachandran, 1999). Failure to adhere to ART medication regimen can result in poor health outcomes leading to opportunistic infections, medication-resistant strains of HIV (McPherson-Baker et al., 2000), and early mortality (Zgibor et al., 2004).

Despite considerable research focused on individual-level barriers, structural barriers to adherence have received much less attention in the ART adherence literature. Structural factors are broad-based forms of social construction, including legal, political, and environmental factors that act as barriers or facilitators to the activities in which people engage (Shriver, Everett, & Morin, 2000). These include poor access to transport (Kagee, Le Roux, & Dick, 2007), the uncertainty of food (Hardon et al., 2007), and lost wages when having to attend clinic visits (Kagee, Remien, et al., 2007). Nattrass (2004) has shown that the availability of disability grants for AIDS patients has acted as a perverse disincentive to medication adherence. Further, overloaded health care facilities (Medicines Sans Frontiers, 2007), pressure on clinic staff (Swartz & Dick, 2002), and poor health literacy (Kalichman & Simbayi, 2004) have been shown to correlate with poor ART adherence. The present study sought to understand what nurses and doctors providing services to ART users thought were the chief structural barriers to adherence that their patients experienced.

Methods

Participants

The sample consisted of six medical staff at the Infectious Diseases Clinic (IDC) of a peri-urban hospital in South Africa.

Procedures

We made initial contact with the head of the IDC who then gave us permission to approach the health care worker (HCW) providing services to patients receiving ART. After an initial meeting with each HCW, we obtained their consent to participate in the study and scheduled an interview. The purpose of these qualitative interviews was to gain an understanding of HCW’s perspectives of the structural barriers to

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ART adherence. The interviewers asked open-ended questions to learn participants’ understanding of the structural barriers to ART adherence faced by patients living with HIV. The core areas covered in the interviews were: (1) patients’ experience of the health care system; (2) patients’ main difficulties in attending clinic appointments and taking medication; (3) impressions of patients’ experiences of the clinic; and (4) potential changes to the clinic system that would ameliorate the problems identified.

**Ethical procedures**

We obtained permission to conduct the study from the Health Research Ethics Committee of Stellenbosch University, the Western Cape Department of Health, the Hospital Superintendent, and the Head of the IDC. All names have been changed to protect the anonymity of respondents.

**Data analysis**

The interviews were tape recorded, transcribed, and entered into the Atlas.ti 4.2 computer program, which assists in the analysis of qualitative data. It facilitates textual analysis and interpretation, particularly selecting, coding, annotation, and comparing important segments of text. Before proper coding commenced, a cadre of four coders practiced coding until a consensus level of over 80% was reached. Once the text had been coded, subsequent networks and themes were constructed to group relevant categories together.

**Results**

**Institution-related barriers**

**Clinic infrastructure**

HCWs stated that the clinic infrastructure impeded privacy, particularly rooms in which patients could discuss personal problems that impeded their medication adherence. Sister Berne stated:

There’s actually no privacy for the patient; patients don’t tend to talk or answer questions when the next one is sitting there concentrating on us and not on the sister there, because everything they tell you needs to be in confidence.

This sentiment was shared by other nurses.

**Waiting times**

HCWs identified the long waiting times as a barrier and disincentive to clinic attendance. Dr Makgoba stated: “it is a very long visit to the doctor in one day. I mean, some people wake up at four to come to the clinic, and they only leave at four in the evening.”

**Overcrowding**

The large numbers of patients meant that the clinic was often overcrowded, leading to potential frustration and burnout among staff. As Dr van Staden, an experienced HIV clinician indicated, “We can’t discharge the patients, the numbers keep growing and growing and growing. So, I think, burnout is an issue.” Sister Trane an experienced registered nurse stated “a patient told me the other day that they didn’t want to go to a certain clinic because the staff was actually being rude to them, and sort of stigmatizing them.”

**Language**

Most of the HCWs stated they only had a limited Xhosa (the local indigenous language spoken in the province) available to them. They thus found it difficult to understand patients’ needs. One doctor explained: “you don’t get the nuances or the complicated stories, especially the psycho-social issues that get lost completely. So I think a lot of things are lost in translation.” Without sufficient communication between patient and provider, clinicians are unable to identify and more importantly understand more personal barriers faced by patients attending their clinics.

**Poverty-related barriers**

**Food insecurity**

Food security as a function of poverty emerged as an important barrier to pill-taking. For example, clinicians reported that patients were reluctant to take their medication on an empty stomach even though they had suggested to patients to take their medication regardless of this. The disruption in the regularity of doses due to hunger invariably has severe implications for the progression to AIDS (Hardon et al., 2007).

**Disability grants as disincentives**

In the South African public health system, disability grants are awarded to patients whose CD4 count falls below 200 for a period of six months, as they are ordinarily not able to work in this condition. The assumption is that ART will foster an increase in CD4, resulting in the patient being able to work again.
once he or she returns to health (Nattrass, 2004). HCWs stated that patients sometimes deliberately stopped taking their medication in an attempt to retain a low CD4 count and thus re-qualify for the grant. As stated by Dr Makgoba: “the disability grant issue is a huge issue, because patients initially aren’t often aware of the fact that it is a temporary grant.” This clinician also reported that patients would sometimes also threaten to stop their medication if doctors did not approve the renewal of their disability grant. He stated: “and you want them to continue with their medication. So sometimes they can use it as blackmail, to say that, if you don’t give it to me, I am going to stop my medication.” A doctor’s refusal to support the renewal of a disability grant was thought to strain the doctor–patient relationship and lead to patients possibly dropping out of care.

Cultural- and political-related factors

Stigma
Stigma emerged as a structural barrier as it prevented patients from disclosing their status to persons in their social constellation. Without disclosing, patients therefore found that they had to attend clinics away from their homes so as to minimize the likelihood of being identified by community members. Dr Trane reported:

They do not want to be identified as being HIV positive. They don’t, so sometimes they choose to use clinics that are out of their immediate, sort of, area where they live, because they do not want to be identified by patients.

Non-disclosure made taking medication openly almost impossible. It was also difficult to hide medication at home due to limited privacy and overcrowded living conditions. HCWs stated that patients were reluctant to tell their employers about their status, out of fear that they may lose their jobs, making it difficult for them to take time off work. Sister Berne reported that:

I think it interferes with their ability to work. They don’t want to tell their employers they are HIV positive. So, equally their employers get sick of them, especially in the beginning where they come in once a week, once in every two weeks.

When patients start ART they are expected to be at the clinic for checkups more regularly. Their failure to disclose to employers makes it very difficult for patients to be at the clinic out of fear they may lose their jobs. In the context of high unemployment rates within South Africa, few patients are willing to risk dismissal from their jobs. Optimal adherence requires that patients not only take their medication every day, but also take it at the correct times as well. The fear of being stigmatized in the workplace threatens adherence, but both stigma and non-disclosure threaten employment as well.

Substance abuse
Substance abuse has been identified as an individual barrier to adherence (Trzynka & Erlen, 2004) and the issue emerged as a theme in interviews with HCWs. For example, Sister Maree stated: “then he will go off on a drinking binge . . . and then he won’t take them for five, six days when he is drinking, and then he will start drinking them again.” As Dr Swart observed: “… even if the patients want to stop, there aren’t particular programs.” We have identified the paucity of substance abuse programs as a structural barrier to adherence.

By all accounts it appears that substance abuse is a major problem among ART users (Brandt, 2009) and that alcohol and substance abuse are undermining of the effectiveness of the treatment due to impairments in areas such as memory, concentration, and physical coordination (Nevid, Rathus, & Greene, 2006). Many patients continue to use substances, and it has been estimated that approximately 5% of ART users who need substance abuse treatment actually receive it (B. Myers, personal communication, 5 October, 2009).

Transport
Participants reported that transport difficulties were exacerbated by the occurrence of disruptions in transport services. Often the taxi route would not take patients all the way to the clinic, and patients would have to walk a substantial distance to reach the clinic, even though they were physically ill, fatigued, or traveling with small children. As Sister Maree stated: “here at the clinic it is mostly the distance they have to come, and the transport is very difficult because they stop in town, and then (they) have to walk up to the hospital.”

Migration
HCWs stated that patients often traveled to the Eastern Cape, particularly to attend funerals. This means that they may be not able to attend clinic appointments, and often do not realize that they require transfer letters in order to obtain their medication from clinics in that area. However,
clinicians also reported that patients were reluctant to take their medication when around distant family. Sister Berne reported that: “and they go off to the Eastern Cape with two weeks of medicine, and then you say to them ... well ... why didn’t you go to the clinic ... well none of my family out there knows that I have got HIV.” It appeared that migration affects the continuity of care as patients remain concerned about stigma and potential discrimination from others.

Social discouragers
According to one clinician, some patients were influenced by local charismatic churches that discouraged them from seeking medical care for HIV and AIDS. A nurse stated:

The church does have an influence, (be)cause I had this patient who came to me he said to me, sister I come today to have a test, an HIV test, and I asked him why? He said cause I’m not positive, I was prayed for and I believe I am no more positive.

This sentiment is at least in part driven by poor health literacy, particularly insofar as knowledge about the trajectory of HIV infection is concerned. Patients who have an inaccurate view of the nature of their infection may hold the inaccurate belief that their status may revert from positive to negative. However, the sentiment expressed above is also in part driven by a version of faith that places individual health in the realm of the metaphysical rather than in the domain of individual behavior.

Discussion
This study is among the first to identify the structural barriers to ART adherence from the perspective of HCWs. As such, it supplements the existing literature on personal and psychological barriers to adherence. The themes may be interpreted through the lens of Ecological Systems Theory (EST), in terms of which the microsystem involves an individual’s interaction with family, friends, neighbors, and the church. At this level, an individual is able to build social networks and thereby gain a valuable source of support. Currently, the treatment guidelines within the South African public health system require disclosure to at least one person before patients enroll on the antiretroviral program. It is thought that disclosure, even to one person, signals that the patient has accepted his or her HIV positive status, thus making adherence more likely (South African Department of Health, 2004). With substance abusers the situation is more complicated as rigorous assessment mechanisms are not routinely available in the health system.

The data in this study suggest that individuals who do not disclose their status to more than one person have difficulty in accessing social support from friends or family who may encourage them to attend clinic appointments or remind them to take their medication. Several studies have shown that positive social and family support are associated with relatively good treatment adherence (DiMatteo, 2000; Holstad, Pace, De, & Ura, 2006; Ware et al., 2009). Non-disclosure and stigma disrupt the ability to form social networks in the microsystem. Inadequate interactions within the microsystem may result in a cascade of disruption throughout all tiers of systems of the ecological model (Bronfenbrenner, 1975).

In our data, the mesosystem may be most closely associated with poverty-related barriers. Poverty appears to be associated with several structural barriers such as transport difficulties, food insecurity, reluctance to take time off work, and non-adherence due to disincentives associated with disability grants. Most patients concerned did not reside within walking distance of the clinic and required transport, which was expensive and not always available. Access to treatment is limited when public transport routes do not operate in regions where clinics or hospitals are located (Meyer-Rath & Richter, 2007).

In the context of unemployment statistics of above 20% (Statistics South Africa, 2009), the question of stigma combined with the employment crisis in South Africa yielded a particular mesosystemic barrier to adherence. Clinicians reported that patients were reluctant to forgo a day at work by attending clinic appointments, and apparently felt they could not disclose to their employers due to concerns about being stigmatized.

Moreover, among unemployed patients, many have come to rely on disability grant incentives and are reluctant to lose this source of income. In some communities the disability grant provides almost 50% of household income (Nattrass, 2004). As indicated by the HCWs, patients claimed to be ill-informed about the details of the grant, and subsequently would insist that doctors renew their grants, thus causing interpersonal difficulties and ruptures in these doctor–patient relationships. HCWs also reported that patients would deliberately stop taking their medication in order to renew their grants.

The exosystem is the third component of the ecological model and consists of the political,
economic, and social system within which the micro and mesosystems are located. There is no doubt that economic, political, and social realities play an important role in determining the kinds of services that patients receive, the economic strains they experience, and their vulnerability to dropping out of treatment. The very fact that two health care services exist in South Africa – one private and well resourced, and the other public and comparatively poorly resourced – is a reflection of the economic realities that characterize South African society and indeed many countries in the global South. With a Gini coefficient of 0.68 (Mywage.co.za, 2009), the gap between rich and poor is among the widest in world. Thus for patients living in poverty, the difficulties associated with clinic attendance is endemic and systemically embedded, to the extent that systemic changes are required to yield better patient health outcomes.

An example of a systemic problem is the understaffing of public health clinics. The UNAIDS/WHO (2007) estimates that roughly 32,000 nursing positions are vacant in the public health sector in South Africa, due to non-competitive salaries, incentives to work abroad, and the stress and burnout that occur within the public health center (Kagee, Remien, et al., 2007). The additional workload, interaction with stigmatized and sometimes very ill patients, leads nurses to become ambivalent about the treatment. It is for such reasons that patients may experience negative attitudes from HCWs.

Conclusion

Failure to address the structural barriers faced by so many patients receiving ART can lead to increased rates of opportunistic infections (McPherson-Baker et al., 2000), increased HIV incidence (Zgibor et al., 2004), and increased mortality rates. These will have further repercussions such as worker absenteeism, child-headed households, and the downward economic spiral associated with these phenomena, in addition to the social sequelae on the physical and psychological well-being of patients and their families. There are various ways in which structural barriers may be addressed. These include greater funding to the health care system so as to employ more HCWs and create an infrastructure more amenable to patient confidentiality, social awareness programs to reduce societal stigma, treatment support grants to substitute disability grants, and transport coupons. Clearly further research is needed to explore the feasibility of these measures.

The themes that emerged from this study provide novel insights into the nature of structural barriers. A systemic understanding of the problems patients face permits researchers, clinicians, and policy-makers to develop approaches to eradicate or ameliorate barriers where this is possible. Alternatively, in cases where such amelioration is not possible, data such as these may be helpful in developing strategies to assist patients to develop the interpersonal, psychological, problem-solving skills that may help them negotiate their environment in an effective way.

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