Dedicated HIV clinics can aggravate or alleviate access barriers to chronic antiretroviral therapy care in resource-poor settings: a longitudinal qualitative study

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Abstract:

Background

With this study, we sought to identify strategies to through which HIV clinics in poor-resource settings can promote access and utilization of ART. We systematically explored pathways followed by health care users through the health system to locate potential areas likely to benefit from systems strengthening initiatives.

Methods

An in-depth qualitative study was conducted in rural South Africa with a purposeful sample of 32 adult patients seeking and/or using ART. Participants were interviewed on monthly basis, on average 4 times in total (Range 3-7), about their experiences with HIV diagnosis, ART access, and overall HIV-related health care utilisation. Data were coded and themes generated through inductive content analysis, and verified using directed content analysis. Systems Theory was used to guide the coding process and interpretation of data. Ethical considerations were observed, and pseudonyms are used.

Results

In order to get to the ART clinic, participants had to negotiate leave from work with employers, abandon steady jobs, relocate from cities to rural villages, deceive powerful authority figures (e.g. traditional healers) and raise transport money. In the ART clinic, participants were often met with inadequate, conflicting and potentially harmful health information, which at times resulted in participants not seeking needed care or seeking care elsewhere. Late arrival and absenteeism of doctors and pharmacists compounded existing human resource shortages. However, patients circumvented barriers by manipulating queues, patient-patient interactions, forming partnerships with health staff and tapping into their own personal resources and social networks. Also, some providers were able to accommodate participants' extenuating circumstances or go 'beyond the call of duty' to assist a patient.

Conclusion

In this study, respondents have had to overcome social barriers before reaching the ART service point, and for this reason, health providers need to go an extra mile in assisting those patients who have successfully entered the ART clinic. Furthermore, health providers have the capacity to minimize social barriers impeding patient attendance at the ART clinic, and this role should be promoted and nurtured. Empowerment of patients with appropriate and adequate health information may serve to promote self-sufficiency and active participation in health care, with the potential to reduce access barriers where health systems fail without depleting personal resources.

Key words:

Antiretroviral treatment,

HIV,

Rural,

Access,

South Africa

Introduction

Human immune-deficiency virus and the acquired immune-deficiency syndrome (HIV/AIDS) remain a chronic life-threatening medical condition. However, HIV/AIDS is not only a chronic infectious medical condition, but has also long been regarded as a social phenomenon (Velimirovic, 1987). On the one hand, ART care-seeking behaviour among HIV/AIDS users is known to occur in the backdrop of a complex plural health care system in resource-limited settings (Moshabela et al. 2011, Peltzer et al. 2009). On the other hand, individual and social factors influence ART care-seeking behaviour among HIV/AIDS patients in low-resource areas, and these include long distance to facilities, high costs of transportation, inability to take time off work and poor quality of health care services (Miller et al. 2010, Etienne et al. 2010, Cooke et al. 2010, Harries et al. 2010, Posse et al. 2009). Thus, ART care-seeking behaviour can be understood as a function of interactions between two worlds, namely, the multi-layered hierarchical system of ART care delivery and the complex social world within which the users reside and network.

Notably, both demand and supply factors, as well as their interactions, need to be considered in shaping health systems to improve access to ART care (McIntyre et al. 2009). In many instances, these diverse factors have been independently or jointly implicated in low uptake of ART, poor treatment adherence and increases in loss of patients from HIV care services (Basset et al. 2009, Merten et al. 2010, Miller et al. 2010). Furthermore, care-seeking behaviour is one dimension of health-seeking behaviour, and involves the act of seeking and using health care, which is best understood through experiences of health care users within the health care system (Mackian et al. 2004). According to Schneider et al., there is a need to recognise that patients are not passive players in health care encounters (2010). Therefore, achievement of desired health care outcomes for people living with HIV/AIDS, as well as the much-needed HIV-related public health impacts, will require optimisation of ART care-seeking behaviour, including medical, individual and social factors, in favour of uptake, adherence and patient retention in care.

By investigating specific sources of weakness in the pathways of care followed by ART care-seeking users through the health care system, and tactics that users employ to overcome ART access barriers (Schneider et al. 2010), one may locate potential points likely to benefit from systems strengthening interventions to increase patient retention in care. With this study, our aim was to identify opportunities and strategies through which HIV clinics in poorly-resourced environments can enhance service delivery so as to promote access to and utilisation of ART. From a user perspective, we tracked longitudinally the experiences of HIV/AIDS clinic users seeking and using ART in rural South Africa. Implementing effective strategies that improves patient experiences and perceptions of HIV clinics may result in increased retention in care. In order to address this question, we employed the principle of general systems theory, which posits that all levels of an organisation are linked to each other in hierarchical relationships so that a change in one level affect changes in the others. Systems Theory is said to be a promising framework to studying the interrelated processes of HIV disease and medical care, a large part of which occurs in a multi-layered health care system (Mkanta and Uphold, 2006).

Methods

Study design and setting

An in-depth longitudinal qualitative study was conducted in rural Bushbuckridge, Mpumalanga Province, South Africa. The antenatal care HIV prevalence is 36% (DOH, 2010), and the antiretroviral treatment roll-out began in 2004. Three hospitals serve a total population of 523 000 in Bushbuckridge. The population is largely poor, with 60% and 20% of men and women respectively declared circular labor migrants (Clark). The area is designated as one of the 13 most rural nodes of poverty and in need of development and densely-settled. Bushbuckridge is surrounded by the Kruger National Park, and many other private game reserves, a major attraction for tourists. High levels of labor migration characterize the area, resulting in large numbers of female-headed

households (Collinson), and the HIV/AIDS-sick circular labor migrants are known to 'return home to die' (Clark).

Data collection and management

The research was conducted between May 2006 and April 2007. For one month prior to data collection, researchers attended daily support groups in the HIV clinic at the local hospital. Purposive sampling was used to recruit adult participants aged 18 years and older from these support groups, based on their likelihood to provide information-rich interviews. Both ART-initiated and non-initiated participants were included. Efforts were made to ensure a similar gender profile among participants to that found in the HIV clinic, and a wide-ranging age distribution.

Participants were asked about their socio-demographic background, and their experiences around HIV diagnosis, antiretroviral treatment use, and use of health care in relation to their HIV/AIDS illness, including traditional forms of health care. Face-to-face interviews were conducted in the preferred language of the patient, most commonly in the local Shangaan. Field notes were transcribed, and data was imported, managed and analyzed using NUD*IST (N6).

A total of 32 participants were included in the study (Table 1). On average, 4 interviews per participant were conducted with a range 3 to 7. One participant was lost to follow-up and there was one death. The duration of interviews ranged from 20 minutes to 2 hours. At follow up, new data was collected and member-checking was done by allowing participants to corroborate findings from previous interviews (Cresswell).

Data reduction and analysis

Inductive content analysis method was used to identify applicable codes (Hsieh). The codes were later grouped into sub-categories and broader categories, which were tested and where necessary recoded using directed content analysis (Hsieh). This coding scheme was applied consistently to all participants included in the study. Codes were identified through immersion and repeated reading of

the text to achieve data familiarity, and documentation was achieved through multiple stages of free-writing and crafting of thematic outputs. Supporting quotes and descriptive summaries are presented as evidence to support thematic interpretation of study findings. Six case summaries considered representative of thematic outputs are presented in text boxes for reference. Pseudonyms were used in all case summaries.

Ethical considerations

Verbal consent was obtained for researcher attendance at the support groups, and all participants signed a written informed consent before the first interview began. Ethical approvals were obtained from the University of Witwatersrand and Brown University. All interviews were conducted in private locations agreed to by both the interviewers and the participants. Some participants agreed to be interviewed in their homes or at convenient locations near their homes at follow-up. No audio-recording was done during interviews because the majority of participants decided against it. In reporting findings, we have removed all identifying data, and have used pseudonyms instead of real names.

Results

Access barriers in getting to the clinic

Respondents in this study have encountered and overcome certain hurdles in their pathways of care. These include negotiating leave from work with employers, abandoning steady jobs, relocating from cities to villages, deceiving powerful authority figures such as traditional healers and raising the much-needed transport money so as to get to the clinic. Thomas in Box 1, struggled to have his HIV infection diagnosed by physicians, and a sense of relief was associated with a positive diagnosis. However, he had to leave his job and relocate to his local village in order to receive care and treatment. For Hlupheka in Box 2, telling lies to his uncooperative traditional healer was his chosen tactic to finally undergo an HIV test. In addition, his work environment made it difficult for him to

attend clinic visits. However, his story revealed the ability of the HIV clinic team to accommodate extenuating social circumstances for certain individuals. This form of personalized service is also echoed by Paul, who was allowed to visit the clinic on another day in order to attend to a pressing personal engagement for a part-time job opportunity. Therefore, by the time respondents arrive at the HIV clinic, many would have had to overcome several access barriers. More typical is the challenge of raising transport money, to which different respondents cope differently. For example, Susan and Thembi lived in villages relatively close to the hospital, and both required R10 (USD1.4) to make a round-trip to the clinic. However, Susan was unable to regularly attend the clinic because of inability to raise transport money, and while Thembi did not have the money either, she was able to raise it in time for her clinic appointments. In the hospital, respondents had to navigate the system of health care, as demonstrated by Helen who on her first day did not know whether to go to the HIV clinic or TB ward as she was presenting with both problems, and it took a while before she was properly guided. At the hospital gate, Thomas had to conceal his green clinic card so that security guards did not recognize that he was visiting an HIV clinic.

Using a multi-disciplinary team in the clinic

The HIV clinic team included doctors, nurse clinicians, pharmacists, dieticians, administrators, lay health workers and other allied workers. Respondent experiences with each one of them appear to influence access to HIV care. Brenda in Box 3 and Lindy in Box 4 inquired about CD4 count-related concerns with a clinic administrator and a dietician respectively. Brenda was given a rude response by the same administrator who previously refused to enter her name in the ART literacy register. Although the Dietician addressed Lindy's response, this was seemingly in conflict with the explanation provided by the doctor. Respondents did not necessarily know who was a clinician or administrator per se, but knew their names, and they sometimes referred to admin staff as clinicians. Mercy observed that "People who are very sick are not well-treated. They sit for a long time, and when they get tired and want to sleep, they are told 'Oh no! you can't sleep here!' by the

admin people." She indicated how one of the administrators "…lacks respect even for older people, and talks to them like they are children". When Mercy confronted her at some point, the administrator said that "You must not come in everyday because you'll teach these other people to talk like you". The exchange between the respondent and the administrator highlights the extent to which respect is valued by the clinic attendees, and the importance of attitude portrayed by different members of the multidisciplinary team, not only clinical providers. The multidisciplinary team in the HIV clinic is further connected to other providers outside the clinic through referrals, as seen with Lindy's referral to the eye clinic. Lindy attempted to use the eye services, but failed because she did not have a referral letter. A different example of failed referral was with Thandi, who presented to the clinic with a problem in her lower leg making it difficult for her to walk and impossible to run. She was referred to a physiotherapist without clear information, and she chose not to go because she was fearful they will put in metal rods that will immobilize her even worse.

Patient visits, waiting and flow through the clinic

Hlupheka and Brenda indicated the problem of multiple visits scheduled around the time of treatment initiation. Brenda was not able to establish reasons for the multiplicity of visits, such that she kept requesting a refill for 2 months. In light of her service delivery concerns and education commitments, she preferred to come less often to the clinic. Although the visits got easier over time and eventually occurred monthly for Hlupheka, he struggled with what appears to be waiting on the grounds of 'trivial' reasons, such as a signature from a doctor, especially when doctors were in such short supply. Lindy reported frustrations with an absent pharmacist delaying her treatment collection, a concern similar to Mabuti's, who said "The pharmacist should be available when the clinic opens. Usually he does not arrive until 10am." Phumzile raised problems about late arrival of the pharmacist, as well as shortage of treatment supply, necessitating a return visit to the clinic to only collect medicines. Phumzile's daughter collected epileptic medicines on a different date from the children's clinic, not coordinated with the HIV clinic visit, and therefore warranting additional

visits. Lindy further highlighted challenges with uncoordinated patient movements through the clinic, whereby some late-comers were seen earlier by the pharmacist, resulting in long waiting periods for other attendees. Thuli suggested that patients be seen according to the numbers received at entrance for all the different queues in the clinic to allow early birds to leave first. Thembi supported this suggestion after witnessing a functioning example of using the same numbers throughout the day at an HIV clinic located in a nearby hospital. In light of long waiting periods, Mkhonto in Box 5 suggested that comfort be ensured by changing the benches in the waiting room. Sometimes clinicians are not able to see all the patients, and therefore request them to return the following day, as was experienced by Madala and his wife, but they insisted on being seen the same day. For Antony, the problem was finishing at the clinic late, only finding that public transport to his village was no longer available, and having to travel after sunset, which may not be safe.

Patient-provider (clinicians) relationships

Mkhonto's story highlights several access barriers that may be encountered by patients in the HIV clinic. Firstly, gender imbalances between patients and providers, in the context of localized rural communities, may hinder access to proper clinical examinations and life-saving interventions in a suicidal person. Secondly, lack of courtesy by clinicians often manifesting by rude behavior created barriers to receive the needed care. The same rude clinician was also identified by Johnny and Madala. As a result, Mkhonto, his wife Winnie and Madala avoided seeing her by letting people behind them to pass through when she invited the next patient and they happened to be next in line. Thirdly, failure to track blood results left some patients dissatisfied with care, and actually reminded of specific clinicians who made efforts to find results for patients. Fourthly, patients were compelled to tap into their resources and support networks to help them cope with failures in the HIV clinic, such as making phone calls to establish names of previously prescribed medicines. This ability to be resourceful and creative in order to overcome barriers was only seen in a few respondents. In addition, providers formed partnerships with patients as seen with Thomas when he

was requested by the clinicians to trace a patient, and he did so successfully. He was also asked to sell Mopani worms for an administrator in the support group room. Meddling of patient-provider relationships may occur, as demonstrated by Calvin, who allowed his sister to collect disability grant money on his behalf only to find that some of it was missing. When he confronted her about it, she came to the HIV clinic to tell clinicians that Calvin misused his grant by buying beer, and the clinicians threatened to terminate the grant. Marumbu was eager to begin receiving his disability grant recommended by clinicians to buy food. He had to sell spinach to collect money for transport or borrow in order to get to the clinic. The case of Busi in Box 6 also highlights the value of poverty and hunger relief played by the HIV clinic through disability grants.

Adequacy and clarity of health information

Most respondents complained of lack of explanations for symptoms, blood collection and other medical procedures. Mary presented with symptoms at her fourth and fifth interviews, but clinicians did not explain to her what was wrong. On her sixth interview, she had decided to consult at her local clinic with persisting symptoms, and she experienced some relief. She was however worried that these symptoms were caused by her ART. Failure to address her concerns may have led Mary to seek care elsewhere. Phumzile felt comfortable asking questions, but realized that on two occasions her questions could not be answered. For Marumbu, he was placed on a food and water fast during a hospital admission, while taking ART from the clinic. He had to argue with a nurse to be allowed to take his ART because of an imposed fast. His case highlighted the need for information to filter through into the hospital wards from the HIV clinic, so that consistency in messaging can prevail. Songeni chose not to ask questions sometimes because "…clinicians know what they are doing". Songeni appeared helpless, as was the respondent who said "It might not be good to ask questions of clinicians, as it might appear as though you are telling them how to do their jobs", and thereby unwilling to question authority. Calvin engaged in a patient-to-patient interaction to generate information. Calvin had no idea what the multiple blood collection was for, and decided to ask other

patients. They all responded that it was to “check the blood”. The provider who advised Busi to buy yoghurts for her children may have driven her further into poverty without knowing. The accuracy of her advice, as well as its appropriateness for Busi’s case remains questionable. Hlupheka was told to avoid sex, avoid drugs and eat vegetables after he wanted to know if his CD4 would increase, and he doubtful about the vegetables. Similar responses were given to many other respondents, and the standardized nature of these messages may have not been relevant as they were not tailored to their needs.

Discussion

In this longitudinal qualitative study, we draw from documented experiences of patients already using HIV/AIDS services in rural South Africa to highlight five key lessons worth noting if better access to ART and improved retention of patients in care are to be achieved. Firstly, patients succeeding in entering a health system have already had to overcome other barriers between their homes and the health facility. Secondly, upon entering the health system, patients have to face and cross several stages of interaction with the health system, and each stage appears to occupy its own sphere of influence and potentially facilitate or obstruct access to ART. Thirdly, health providers have the capacity to provide individualised or tailored care that can minimise access barriers to ART. Fourthly, some patients using HIV clinics have the ability to overcome barriers within the health system, whereas others do not seem to display this self-sufficiency. Finally, patients’ ability to use the HIV clinic can be enhanced by provision of relevant and appropriate information through improved communication between the different spheres of the health service, between the health service and patients, and among patients themselves. We discuss here the implications of each lesson learned, with relevance to promotion of ART access and curtailment of patient losses.

We have demonstrated that patients succeeding in arriving at the ART facility do so after having had to overcome access barriers caused by uncooperative authority figures, non-conducive residential locations and strenuous jobs, in addition to some already known ones, such as transport costs,

opportunity costs and long distances to ART facilities (Posse et al. 2009, Harries et al. 2010, Miller et al. 2010). These access barriers may persist or resurface at one point or another in the process of chronically caring for HIV patients. These changing patterns over time suggest that successful initial access to ART care does not necessarily secure future use of health care (Cornell et al. 2010). Therefore, health providers in the HIV clinic need to be supportive to patients who successfully reach the ART facility, attempt to minimise health system-based access barriers, and make additional efforts in assisting these patients with access to needed care. Health workers could promote patients' pleasant experiences with health care, especially with matters within the providers' own sphere of influence (Miller et al. 2010). For example, ensuring less frequent and timely completion of clinic visits may help reduce consumption of patient resources and time, and protect patient jobs and physical safety. Also, an effort to track and retrieve laboratory results may reduce physical discomfort associated with repeated collection of blood specimens and anxiety since progression of disease and treatment is monitored through these results (Cornell et al. 2010).

Furthermore, providers need to be on the lookout for patients with socio-economic factors that may impede patient's ability to return for care. Although the scope of work performed by health providers may not be designed to immediately address patients' socio-economic concerns, this study demonstrate that health providers drawing from the multidisciplinary team may successfully work with patients to curb some of these access barriers by providing tailored care. For example, rescheduling clinic visits and fast-tracking individual patients through the queue may help minimise treatment interruptions and avoid monetary losses in opportunity costs. In addition, many patients in this study appear to rely largely on a disability grant, which is largely controlled by health providers, for food and other social expenses. Therefore, sensitizing health providers to such barriers may enhance their own capacity to reduce barriers as well as promote their role in empowering patients to overcome barriers (Miller et al. 2010).

In the context of overburdened health systems, resourcefulness, agency and self-sufficiency displayed by patients may be instrumental for improved access, and perhaps should be nurtured (Bandura et al.). Disempowered patients seem to accept poor quality of care, whereas more assertive patients appear to employ certain creative manoeuvres to increase their opportunities in using health care (Schneider et al. 2010). These patients raise capital to finance their HIV clinic visits by borrowing money or through small businesses, avoid entering consultation rooms of rude health providers, make phone calls to their partners in an effort to identify names of drugs when they should be written in the medical records, and use a white out-patient department patient-carried card as opposed to a stigmatising green HIV clinic one. In addition, patients ask each other questions in the HIV clinic when they do not understand procedures, and therefore influence each other's views and experiences of clinic processes. Furthermore, certain patients may form partnerships with health providers to trace patients, and most likely be rewarded with easier access to health care (Ware et al. 2009). These patient-to-patient socialisation and patient-provider partnerships require further research to elucidate their impact.

As stated above, patients seem to confront several stages of interaction in the health system. On the demand side, patients appear to interact with other patients while awaiting their consultations. On the supply side, 3 such spheres are identified: the inner sphere of patient-provider relationship, the middle sphere of the HIV clinic multidisciplinary team, and the outer sphere of additional members within the broader health facility, who may be connected directly or indirectly to the HIV clinic. All these levels are linked to each other through the paths that are created patients. In this study, patients have had to overcome risk of stigma at the hospital while negotiating access with a security guard, attempt to reason with a ward nurse insisting on breaking adherence to ART due to an imposed fast, and miss an opportunity to consult an eye doctor because user fees were required after a fee-exempting referral letter was not granted by the HIV clinic. A common theme in these scenarios is the occurrence of avoidable barriers to access in the broader system of health care delivery, but beyond the HIV clinic itself. We observed that patients may not necessarily distinguish

between different members of the multidisciplinary team, highlighting the importance of each team member's role independently. As shown in this study, a patient may ask a dietician or an administrator the same question initially posed to a doctor. However, since patients view the multidisciplinary team as a network of providers, and not necessarily hierarchical or departmentalised, a well-coordinated team effort to minimise barriers may be essential over and above initiatives of each team member.

In this study, we note several factors that may hinder successful realisation of access through the nature of a patient-provider relationship. Firstly, gender inequities between patients and providers in the context of socio-cultural factors may limit opportunities to receive a life-saving intervention. Secondly, lack of adequate and relevant information may reduce patients' ability to understand the need for medical procedures and continued use of health services. In this study, lack of explanations for symptoms by providers was shown to lead patients to seek care elsewhere. Yet, failure to answer questions, lack of consistency in messaging, and conflicting, overly standardised, inaccurate and inappropriate messages were common problems encountered by respondents. In addition, as in the case of 'Danone' yoghurt, a well-intentioned advice may be inappropriate for a particular individual, or even harmful. Thirdly, the unprofessional behaviour of health providers may result in poor perceived quality of care, which is known to promote loss to follow up in ART patients (Miller et al. 2010, Etienne et al. 2010). Rudeness, absenteeism and late arrivals were highlighted by several respondents as problematic. In this study, rudeness led to non-disclosure of health concerns and clinician avoidance by patients.

The limitations of this study were as follows: first, all respondents in this study may be considered successful users for they were all sampled from the HIV clinic, second,

In conclusion, HIV clinic users in rural South Africa face access barriers that may change over time. Therefore, health providers need to be able to identify and respond to these barriers timely and appropriately. While the role of a patient-provider relationship is also well-established (Street jnr et

al. 2010, Schneider et al. 2010), a more humane and caring environment may help patients cope better with difficulties. The quality of care provided by the HIV clinic and other parts of a health system need to be improved through deliberate efforts to promote pleasant experiences of health care by ART-using patients even within the constraints of resources. Reducing fragmentation and strengthening linkages between different parts of the health system and reducing health system-based stigma may serve to improve access to health care (Topp et al. 2010, Pfeiffer et al. 2010). The self-sufficiency demonstrated by some users need to be nurtured and encouraged through patient empowerment, particularly through clear tailored health messaging. Better linkages between and within different parts of the health care delivery system are urgently needed, and the potential for partnerships between patients and the health system need to be investigated. Therefore, emphasis should be placed on this dynamic constantly-changing patient-health system relationship beyond patient-provider relationships, which should also be seen in the context of multidisciplinary teams rather than only patients and clinicians.

Box 1

Thomas is 55-year old man estranged from his wife and children. When he fell ill, he sought help from multiple physicians to no avail. After learning his HIV+ status, he was relieved because he finally knew the cause of all of his illnesses. He left his job in the city and came back to [his local village] and had subsequently stayed because treatment was available. When he initiated on ART, his CD4+ count was 15, but the most recent CD4+ count was 105. He is happy with clinicians at [the HIV clinic]. He understands services they provide for him: they administer ARVs, sometimes people at admin desk give him Mopani worms to sell at the support sessions, and they collect blood. The clinicians never explain what the blood collection is for, and he has never asked. When he comes to the HIV clinic at the hospital, he must show identification to get through the gate. “This is problematic because the [HIV clinic] cards are green, so the security guards know that you are going to the HIV clinic.” Instead, he shows his white Out-Patient Department card. He is at [the HIV clinic] today to report back to the clinicians about a patient he had been solicited to trace, whom he was able to find.

Box 2

Hlupheka is a young 26-year old male who attended 5 monthly interviews. He had been living with HIV for 3 years and initiated on ART for 18 months on his first interview. He feels much better since he commenced ART, and his CD4 count has increased from 180 to 311. Starting treatment meant that he had to come to [the HIV] clinic approximately 4 times per month, but now he only attends once per months on his appointment days because support group sessions are full. He felt that doctors need to always be available. On the day of his second interview he finished early in the clinic, but had to wait only for the doctor's signature on his chart. He has had to overcome numerous barriers to attend the clinic. When he first decided to test for HIV, the traditional healer he was consulting with did not want him to go get an HIV test. He lied to the healer and told him that he was going to the hospital for to have a tooth removed, but instead received counselling and testing. On his fourth interview, he reported having missed his previous clinic appointment because his employer would not let him off work to travel for treatment collection. He was only able to convince his employer to allow him to leave the premises after work on his day of clinic appointment, and to concede 1 hour off from work the next morning. He took a taxi and arrived at [the HIV] clinic early the next morning, explained his problem to the clinicians, who were able to push him through the queue, and he was able to take a taxi and arrive 30 minutes later than expected.

Box 3

Brenda is 32 years old, a mother of two kids and a nursing student in the city. On her first interview, she had only been on ART for 2 weeks and was visiting [the HIV] clinic about twice per month. She would come less often, and she is confused as to why she has come so frequently to just collect treatment. She felt there should be a strategy developed to allow patients to collect more than one month supply of treatment. On her two –week appointment, she learned that although the CD4 count used to initiate her on ART was 131 and meeting the required criteria of CD4 count below 200, the CD4 count collected at baseline initiation of ART was 641, and very high. She was confused as to whether she was supposed to be on ART or not, and concerned because she had already started taking treatment. She never contemplated stopping treatment before discussing the matter with the clinicians. However, she received a rude response when she asked the clinic admin desk about it, "Why are you asking me, I am not the doctor!" Weeks earlier, the same administrator had refused to document her attendance at one of the ART literacy classes required for ART initiation. She expressed concerns about her CD4 count with a nurse clinician, who was unable to answer her questions, but recommended she speaks to a doctor. At her most recent visit, one clinician yelled at Brenda to stop her child from touching the paperwork, and when she requested treatment for piles, the clinician asked her "Why couldn't you simply buy it at the chemist yourself?" Brenda felt the dietician must improve her services, "she doesn't give food supplements universally, and they are only given to the few people who arrive early. Patients who are late do not get supplements because they are finished early."

Box 4

Lindy had been on ART for 9 months when she was first interviewed, and received 4 other monthly interviews during the study. Her main concern was the erratic CD4 count levels, which could not be explained by clinicians. Her initial CD4 count was 159, increased to 352, and then dropped to 292. One of the doctors thought that this was due to her arm that was recovering from shingles. The dietician told her that ART often times causes other diseases. On her fourth interview, her new CD4 count was 360. She was frustrated because she had been at the clinic all day and it was already afternoon, but the pharmacist had not arrived. Patients were told that another pharmacist would be coming to fill in for the missing one, but he or she had still not shown. On her third interview she complained that some people who arrive late are somehow seen earlier by the pharmacist than those who were early. Although patients are given numbers upon arrival at the clinic to wait in the clinician consultation line, these numbers are not used to queue up for additional services such as blood or treatment collection. She was also referred by [the HIV] clinic to the eye clinic previously, but was not seen because the HIV clinic doctor did not write a referral letter. Without a letter, she would have had to pay for the eye consultation. If she could change anything, she would 'address the apparent shortage of staff, because clinic visits are too long.'

Box 5

Mkhonto is a 43-year old married man with a history of illicit drug use that began when he was a soldier abroad, helping him to calm his nerves. In the process of the 5 monthly follow up interviews, he reported suicidal intentions to the interviewer, who encouraged him to communicate his feelings to the clinicians, and followed up with Mkhonto to ensure that a discussion of his suicidal intentions occurred. When he consulted with the female nurse clinician, she did not want to examine his genital sores because she knew his wife well and he was 'like a brother to her', and he therefore decided not to disclose his suicidal ideas. Following the consultation, the interviewer reported the matter to the physician-in-charge of the clinic and requested him to intervene, and a lengthy consultation with Mkhonto ensued, and later involved his wife to help address their strained relationship, his affair and his suicidal intentions. Mkhonto singled out another nurse clinician who treated patients poorly, because she yells at them when they see her for blood collection (Non-disclosure to clinicians in Hlamalani 116 for fear of yells), and gets irritated when patients do not place their arms in a position she wants. They never explain what the blood is for, but he assumes it is collected to examine his viral load although he has yet to see the results. The clinicians keep telling him his blood results are lost. His blood was drawn monthly over 3 months, but he never got his results. "There used to be a woman who would personally follow up missing results of blood tests. Now clinicians don't know anything and cannot answer my questions when results are missing. In addition, they had no recollection of pills I got previously for my leg pains, and did not even look up previous prescriptions in my chart. Instead, I had to call my wife to figure out the name of the pills." The same thing happened with the eye drops he was using. "Basically, the services are bad and getting worse". He would also "…change the benches in the waiting area, because they are very hard and it's painful to sit on them for extended periods of time.

Box 6

Busi is 36-year old mother of three who is also training to become a traditional healer. Since being taken off the disability grant [820], she has had difficulty acquiring food. She hasn't purchased food in the past month, nor has she eaten for the past three days. She 'is living on water.' As for her children, the subject's sister provides them with meals, but the subject feels uncomfortable asking for food for herself because the sister and her husband rely on three CSGs [190x3] to support their family only. At the end of the month, the subject's brother gave her 200 Rand [USD] to buy groceries for the family. She thinks that he may continue buying groceries for her. While the subject still receives a CSG, she utilizes most of this money to purchase soap and other toiletries for the household, and to buy 'Danone' yogurts for her children, as this is recommended by the nurse at Cottondale Clinic.