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## Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya

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**Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya**

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Journal Selection:	AIDS Care
Keywords:	HIV, ART, Kibera slum, Poverty, Qualitative



REASONS FOR UNSATISFACTORY ACCEPTANCE OF ANTIRETROVIRAL  
TREATMENT IN THE URBAN KIBERA SLUM, KENYA

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For Peer Review Only

**SUMMARY**

The aim of this study was to explore why patients in the urban Kibera slum, Nairobi, Kenya, offered free antiretroviral treatment (ART) at the Médecins Sans Frontières (MSF) clinic, choose not to be treated despite signs of AIDS. Qualitative semi-structured interviews were conducted with 26 patients, 9 men and 17 women. Six main reasons emerged for not accepting ART; a) fear of taking medication on an empty stomach due to lack of food; b) fear that side-effects associated with ART would make one more ill; c) fear of disclosure and its possible negative repercussions; d) concern for continuity of treatment and care; e) conflicting information from religious leaders and community, and seeking alternative care (e.g. traditional medicine); f) illiteracy making patients unable to understand the information given by health workers.

**KEY WORDS:** HIV, ART, Kenya, nutrition, Kibera slum, fear, qualitative, ~~poverty~~,

**Deleted:** This study reveals a number of important operational barriers to ART uptake, which would need to be urgently addressed. ART eligible individuals need to be better informed and supported both at provider and community level to be able to take up the ART offer.

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## INTRODUCTION

The Kibera slum area in Nairobi, Kenya, constitutes a high-risk environment for HIV due to poverty, unemployment, substance abuse and a high frequency of women being involved in commercial sex (Gulis, 2004). Accurate data on the prevalence of HIV/AIDS in Kibera are lacking but it is estimated to be higher than the 9.1% prevalence reported from other areas of urban Nairobi (Central Bureau of Statistics Nairobi, 2003).

Since 2003, Médecins Sans Frontières (MSF) has offered ART free-of-charge to all eligible HIV-positive individuals through three primary health care facilities in Kibera in collaboration with the Kenyan Ministry of Health (MoH). Routine program analysis revealed that a considerable proportion of eligible HIV positive individuals in need and offered ART free of charge were not taking up the offer.

We conducted a qualitative study using in-depth interviews in the urban slum setting of Kibera to explore the reasons why HIV-positive individuals in need of ART choose not to take up the offer.

## METHODS

### ART and study eligibility

All HIV-positive individuals were considered eligible for ART if they were in WHO clinical stage 4 irrespective of CD4 counts, WHO stage 3 with a CD4 count <350 cells/ul or stage 2 with a CD4 count <200 cells/ul. Individuals who were considered eligible for ART but did not take up the offer were considered eligible to participate in this study.

### Interview procedures, data collection and analysis

The interviewees were purposively selected from a list of ART eligible individuals (who opted not to take up ART) to represent different areas in Kibera, different ethnic groups, sexes

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and age groups. They had all earlier met a social worker and given their approval of a home visit. Semi-structured audio-recorded face-to-face interviews were carried out with a total of 26 people, 9 men and 17 women, aged between 23 and 55 years. Data was collected through in-depth face-to-face interviews (duration 30-60 minutes) by a medical doctor together with a female interpreter from Nairobi, who speaks English, Swahili and Kikuyo and is familiar with the context of Kibera. Data was translated, transcribed and analyzed using content analysis, by the authors. Ethical approval was obtained by the MSF Ethical Board (ERB) and from the Kenyan Ministry of Health (MoH).

## RESULTS

There were a total of 69 people considered eligible for interviews and whom we tried to contact. 18 had gone to another NGO and could not be traced, 9 had switched to a traditional doctor, 9 had reported migrating up country, 3 had died and 4 did not want to be interviewed. The 26 remaining patients all accepted to be interviewed (table 1). The only major group not accepting to participate was the Muslim community in Kibera, from which, for unclear reasons, nobody wanted to be interviewed despite being approached twice and invited for interview.

(Table 1)

### Reasons for not accepting ART

The categories emerging from the qualitative analysis were; a) fear of taking medication on an empty stomach due to lack of food; b) fear that side-effects associated with ART would make one more ill; c) fear of disclosure and its possible negative repercussions; d) concern for continuity of treatment and care; e) conflicting information from religious leaders and

**Deleted:** Interviewees were first contacted by a male person living with HIV and AIDS (PLWHA) (D) from the community who was given a list from the MSF-clinic of eligible people who hadn't shown up for starting ART. This was done in collaboration with one of the authors (DS) working as a clinical officers at MSF and one social worker who both knew the context of Kibera well. D was given the name, sex, age, marital status and location of the patient to be interviewed and contacted them in advance in their homes. He presented himself and told them about the interviews, the purpose of the study, how it would be performed and issues about confidentiality. D was thoroughly informed to respect confidentiality and address the question so that nobody around would understand the nature of the visit. He was further informed to avoid disclosure of the patient's HIV status if confronted with other members of the family. D explained that the interviews were to be conducted by researchers from Sweden and Kenya. ¶

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**Deleted:** Three pilot interviews were performed in order to test the question guide, the technique of the interviewer and the translation/transcription process so that improvements and modifications could be made. The interviews took place either in the participant's homes (24) or at a nearby, neutral, location chosen by the participants (2). After the interview participants were offered a lunch. ¶  
The question guide was developed to cover previously identified areas of interest with relation to ART, uptake, adherence and perceptions about side effects and traditional medicine. ¶ (... [8])

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**Deleted:** The patients were initially briefed about the purpose of the study. Written informed consent, or orally explained for those who were illiterate, was then obtained and each patie (... [10])

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Data was analysed using latent content analysis (Graneheim & Lundman, 2004). The transcribed interviews were first read a number of times to get a gener (... [11])

community, and seeking alternative care (e.g. traditional medicine); f) illiteracy making patients unable to understand the information given by health workers, (table2),

(Table 2),

## DISCUSSION

Poverty dominates people's life in urban slums regardless of HIV status. Lack of food and a perceived risk associated with taking ART on an empty stomach was the most important obstacle for accepting ART. As most other ART programmes, MSF/MOH clinics in Kibera did not include food provision at the time of study, but patients were counselled to eat well to avoid side effects and for the drugs to be efficient. Some patients who lacked food at home thus wrongly interpreted this information as "No food=No ART". Addressing the issue of food security and understanding the depth of poverty in settings where ART programs are introduced remains critical for successful initiation of sustainable ART.

The majority of the patients were afraid of the side effects associated with the ART. Many misinterpret the death of family members on ART as caused by the medication rather than opportunistic infections/AIDS. Coping with the initial side effects of ART requires a well-informed client, which is more challenging to achieve in contexts where illiteracy and lack of health staff is a reality (Stevens, Kaye, & Corrah, 2004). Information about side effects was given by health workers and by handing out pamphlets that were copied from earlier ART-programs in South Africa. These pamphlets had an over-emphasis on potential side effects, which might have induced fear in some patients. Most patients interviewed had also none or very basic education and were too embarrassed to reveal their illiteracy or ask for help. Information linked to ART in these settings needs to be well adapted to the local socio-cultural context and communicated through more appropriate channels e.g. through peers

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The combination of poverty, lack of food and fear of side effects from medicines was the main obstacle for most patients to start taking ART. Many patients reported having no job, which hindered them from getting money and thus food for themselves and the family. This 33-year-old woman told us about her lack of means to handle a treatment: ¶

¶ I am not saying that I cannot use the treatment. In fact I would want to live longer, but sometimes I do not have a job. Other times I stay for two days without any food. That makes me afraid of using the medication (33-year-old woman) ... [12]

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informing each other on side effects and how to cope with them (Bangsberg, 2006; Stenson et al., 2005). Studies from India and high income countries have shown that social support, education and trust in the drugs are important factors for disclosure, preparedness and adherence to treatment (Kumarasamy et al., 2005; Remien et al., 2003; Siegel & Schrimshaw, 2005). In a resource-poor context like Kibera, many are diagnosed at a late stage and are in immediate need of treatment (Stringer et al., 2006). They are forced to accept their HIV diagnosis at the same time as they must reveal their status and cope with the idea of life-long treatment. This is probably an important reason for delayed uptake or non-acceptance of ART. Despite the fact that many of the interviewees knew that they needed these drugs to survive, they lacked the power to overcome existing barriers such as unemployment, poverty and stigma.

Stigma associated with HIV prevents many from disclosing their HIV-status limiting their access to treatment. The compulsory disclosure to a treatment buddy or significant other implies compulsory disclosure of HIV status and in a setting where HIV related stigma is high this criteria dissuades some from taking up ART. Fear of violence and exclusion from the family was often mentioned, in particular by women, as a reason for non-disclosure. Their fear also seemed valid since several respondents had been threatened by their spouse or other family members because of HIV, and many had seen others being mistreated in the community. The ethical dilemma of conditioning patients' access to lifesaving treatment on potentially unsafe actions in the current cultural context of stigma must be recognized and further evaluated. Despite occasional awareness campaigns, knowledge about HIV is still rudimentary in Kibera and many of the respondents pointed out the need for increased awareness.

Our findings also indicate that ART providers must become more aware of the importance of religion and traditional medicine in patients' decision-making regarding ART

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and address these issues in a non-judgemental way. While many believe that traditional medicine is the key to fighting HIV in Africa (Homsy, King, Balaba, & Kabatesi, 2004), others point to harmful customs that not only delay the seeking of evidence-base care, but that could even aggravate the disease and kill patients (Munk, 1997). Despite the fact that traditional medicine is the primary source of health care in sub-Saharan Africa, it has received little attention (Mills, Cooper, & Kanfer, 2005; Zachariah et al., 2002). Recently, WHO acknowledged the importance of integrating indigenous medicine with the national health care system (Homsy, King, Balaba, & Kabatesi, 2004; WHO, 2002) a process that has already begun in South Africa (Morris, 2001).

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**Deleted:** Although our respondents expressed ambivalence, many had sought help from traditional healers. Many were also grateful for the support they had received from the church but some respondents were sceptic about the attitude among religious leaders towards ART and safe sex. Some felt confused after religious authorities had asked them to perform rituals in order to get rid of the virus or to be relieved from symptoms.

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The findings from this study have helped to guide a number of urgent policy related changes within the Kibera ART program namely a) all ART eligible positive individuals are offered nutritional supplementation using a ready-to-use food b) all information pamphlets have been reviewed and adapted to the reality of the local context c) the use of other methods of communication e.g. through peer groups, church and traditional leaders have been enhanced d) although encouraged, disclosure of HIV status and the presence of a "treatment buddy" are no longer compulsory to start ART and e) links with other partners and NGOs in Kibera have been enhanced.

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¶ Overall, patients were satisfied with the health services provided at the MSF clinics and trusted the staff, but more emphasis needs to be put on information about side effects, how to deal with food shortages and on addressing patients' concern for continuity of care once the Ministry of Health (MOH) takes over the responsibility. Health care providers also need to find ways to support patients who fear repercussions from their spouse or families through more flexible disclosure criteria, home visits and intensified community awareness campaigns.¶

## REFERENCES

- Bangsberg, D. R. (2006). Monitoring adherence to HIV antiretroviral therapy in routine clinical practice: The past, the present, and the future. *AIDS Behav*, 10(3), 249-251.**
- Central Bureau of Statistics Nairobi, K. (2003). Kenya Demographic and Health Survey 2003. Retrieved 7 September 2006, from <http://www.afronets.org/files/KenyaDHS2003.pdf>**
- Gulis, G. (2004). Health status of people of slums in Nairobi, Kenya. *Environmental research*(96), 219-227.**

- Homsy, J., King, R., Balaba, D., & Kabatesi, D. (2004). Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *Aids*, 18(12), 1723-1725.
- Kumarasamy, N., Safren, S. A., Raminani, S. R., Pickard, R., James, R., Krishnan, A. K., et al. (2005). Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: a qualitative study. *AIDS Patient Care STDS*, 19(8), 526-537.
- Mills, E., Cooper, C., & Kanfer, I. (2005). Traditional African medicine in the treatment of HIV. *Lancet Infect Dis*, 5(8), 465-467.
- Morris, K. (2001). Treating HIV in South Africa--a tale of two systems. *Lancet*, 357(9263), 1190.
- Munk, K. (1997). Traditional healers, traditional hospitals and HIV / AIDS: a case study in KwaZulu-Natal. *AIDS Anal Afr*, 7(6), 10-12.
- Remien, R. H., Hirky, A. E., Johnson, M. O., Weinhardt, L. S., Whittier, D., & Le, G. M. (2003). Adherence to medication treatment: a qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities. *AIDS Behav*, 7(1), 61-72.
- Siegel, K., & Schrimshaw, E. W. (2005). Stress, appraisal, and coping: a comparison of HIV-infected women in the pre-HAART and HAART eras. *J Psychosom Res*, 58(3), 225-233.
- Stenson, A. L., Charalambous, S., Dwaadwa, T., Pemba, L., Du Toit, J. D., Baggaley, R., et al. (2005). Evaluation of antiretroviral therapy (ART)-related counselling in a workplace-based ART implementation programme, South Africa. *AIDS Care*, 17(8), 949-957.
- Stevens, W., Kaye, S., & Corrah, T. (2004). Antiretroviral therapy in Africa. *Bmj*, 328(7434), 280-282.
- Stringer, J. S., Zulu, I., Levv, J., Stringer, E. M., Mwango, A., Chi, B. H., et al. (2006). Rapid scale-up of antiretroviral therapy at primary care sites in Zambia: feasibility and early outcomes. *Jama*, 296(7), 782-793.
- WHO. (2002, 2002). Traditional medicine-Growing needs and Potential. Retrieved September 7, 2006, from [http://whqlibdoc.who.int/hq/2002/WHO\\_EDM\\_2002.4.pdf](http://whqlibdoc.who.int/hq/2002/WHO_EDM_2002.4.pdf)
- Zachariah, R., Nkhoma, W., Harries, A. D., Arendt, V., Chantulo, A., Spielmann, M. P., et al. (2002). Health seeking and sexual behaviour in patients with sexually transmitted infections: the importance of traditional healers in Thyolo, Malawi. *Sex Transm Infect*, 78(2), 127-129.

**Deleted:** Bangsberg, D. R. (2006). Monitoring adherence to HIV antiretroviral therapy in routine clinical practice: The past, the present, and the future. *AIDS Behav*, 10(3), 249-251.¶

Calleja, J. M., Marum, L. H., Carcamo, C. P., Kaetano, L., Muttunga, J., & Way, A. (2005). Lessons learned in the conduct, validation, and interpretation of national population based HIV surveys. *Aids*, 19 Suppl 2, S9-S17.¶

Central Bureau of Statistic Nairobi, K. (2003). Kenya Demographic and Health Survey 2003. Retrieved 7 September 2006, from [http://www.afronets.org/files/KenyaDH\\_S2003.pdf](http://www.afronets.org/files/KenyaDH_S2003.pdf)¶

Chakaya, J. M., Meme, H., Kwamanga, D., Githui, W. A., Onyango-Ouma, W. O., Gicheha, C., et al. (2005). Planning for PPM-DOTS implementation in urban slums in Kenya: knowledge, attitude and practices of private health care providers in Kibera slum, Nairobi. *Int J Tuberc Lung Dis*, 9(4), 403-408.¶

Chemuliti, J. K., Gathura, P. B., Kyule, M. M., & Njeruh, F. M. (2002). Bacteriological qualities of indoor and out-door drinking water in Kibera sub-location of Nairobi, Kenya. *East Afr Med J*, 79(5), 271-273.¶

Crane, J. T., Kawuma, A., Oyugi, J. H., Byakika, J. T., Moss, A., Bourgois, P., et al. (2006). The price of adherence: qualitative findings from HIV positive individuals purchasing fixed-dose combination generic HIV antiretroviral therapy in Kampala, Uganda. *AIDS Behav*, 10(4), 437-442.¶

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 24(2), 105-112.¶

Gulis, G. (2004). Health status of people of slums in Nairobi, Kenya. *Environmental research*(96), 219-227.¶

Homsy, J., King, R., Balaba, D., & Kabatesi, D. (2004). Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *Aids*, 18(12), 1723-1725.¶

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Mills, E., Cooper, C., & Kanfer, I. (2005). Traditional African medicine in the treatment of HIV. *Lancet Infect Dis*, 5(8), 465-467.¶

Morris, K. (2001). Treating HIV in South Africa--a tale of two systems. *Lancet*, 357(9263), 1190.¶

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In the study cohort 801 patients were eligible for ART in the MSF Kibera programme and 455 (56%) of these had not been put on ART.

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eligible individuals choose not to take up an ART offer are at present not well characterized

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were not well characterized and important information for scaling-up access to ART in high-risk contexts.

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### **Study setting and population**

This study was conducted between March and August 2006 in the Kibera slum. Poverty and unemployment is widespread, and most people work in the informal sector (petty trade) (Gulis, 2004). Houses are constructed out of mud or wooden planks with corrugated tin roofs. Eighty-six percent of families live in single rooms with an average family size of four (Chakaya et al., 2005). Garbage piles up in the narrow lanes and sewage canals are lacking. Pipe borne water is very limited and seriously contaminated (Chemuliti, Gathura, Kyule, & Njeruh, 2002). There are high-risk arenas of lively bars and large networks of commercial sex workers. Substance and alcohol abuse is common. Access to health care is generally dismal with the entire population depending on five primary health facilities, three of which are run by MSF and several/informal other health care providers.

### The MSF Programme

MSF started its first HIV/AIDS activities in Nairobi in 1997, and began providing ART in May 2003 at two main locations, one inside the Kibera slum and one at the Mbagathi hospital right outside Kibera. The community-based programme in the Kibera slum is integrated with the health services provided by the MoH at three health-care centres; Lindi, Kibera south health centre and Gatwekera. In Kibera patients have free access to voluntary counselling and testing (VCT). If tested positive for HIV, patients are enrolled in the MSF programme to eventually be put on ART. There are a number of support groups holding regular meetings for the patients to participate in, both organized by MSF and other NGOs.

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defined as eligible for ART at the MSF clinic if they were ART-naïve, had accepted a home visit and classified in: WHO clinical stage 4 or stage 3 with a CD4 count <350 cells/ul or stage 2 with a CD4 count <200 cells/ul. Among these individuals, those who refused to accept ART were considered eligible for this study

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The first-line HAART regimen is a fixed dose combination of Stavudine (d4T), Lamivudine (3TC) and Nevirapine (NVP), (Triomune®). HIV-positive individuals are provided information on ART, its side effects and are educated on the implications of therapy and the need for life-long adherence. A patient information booklet is used to facilitate this process. Blood is collected for a baseline CD4 count and the patient is requested to return in one week at which time, if eligibility criteria are met, the patient along with a guardian participates in a group counselling session (with peers) about ART,

which is followed by an individual counselling session, conducted one week later. One tablet of Triomune® in the morning plus one tablet of a combination of d4T/3TC (Coviro LS®) at night is then prescribed for a period of 14 days. This is followed by one tablet of the fixed dose combination (Triomune®) twice daily. The follow up schedule is then monthly for 3 months, bimonthly until 6 months and by trimester thereafter. ART and laboratory tests are offered free-of-charge by MSF.

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Three pilot interviews were performed in order to test the question guide, the technique of the interviewer and the translation/transcription process so that improvements and modifications could be made. The interviews took place either in the participant's homes (24) or at a nearby, neutral, location chosen by the participants (2). After the interview participants were offered a lunch.

The question guide was developed to cover previously identified areas of interest with relation to ART, uptake, adherence and perceptions about side effects and traditional medicine. The question guide and the consent form, both translated to Swahili were reviewed by three people from PLWHA support groups and by one of the clinical officers.

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Well aware of the potential bias in patient response caused by the presence of a medical doctor, the first author still chose to participate in order to better probe the questions. Most interviews were conducted in Swahili, and the responses were translated into English for the first author in an ongoing fashion during the interview. Christian: I would

put this under the Results section. There were a total of 69 Out of the f 75 people considered eligible for interviews and who we tried to contact. 18 had gone to another NGO and could not be traced, 9 had switched to a traditional doctor, 9 had reported migrating up country, 3 had died and 4 did not want to be interviewed. the studythat contacted, The 26 remaining patients all accepted to be interviewed. Those others who declined had either already gone to another NGO (18), switched to were seeing a traditional doctor (9), had migrated gone up country (9), had died (3), did not want to be interviewed no other reasons given (4) or were already put on ART by MSF (6) (I agree with AME that this should not have been in the denominator, thus the study eligible individuals should total up to 69., said they did not want to be interviewed no other reasons given (4) or had died (3). Two of the patients interviewed were actually not really “defaulters” but were in the process of starting ART. The only major group not accepting to participate was the Muslim community in Kibera, from which, for unclear reasons, nobody wanted to be interviewed despite being approached twice and invited for interview..

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The patients were initially briefed about the purpose of the study. Written informed consent, or orally explained for those who were illiterate, was then obtained and each patient was provided with a copy of the consent form. Nobody refused interviews at this stage and onward. The interviews lasted between 30-60 minutes, were digitally recorded, transcribed verbatim soon after the interviews and then translated from Swahili to English.

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Data was analysed using latent content analysis (Graneheim & Lundman, 2004). The transcribed interviews were first read a number of times to get a general idea of the material and to discuss the essential characteristics of the text. Coding and categorization were then performed inductively in several stages by the first author together with the other co-authors to get better inter-rater reliability. Initially key words and selected sentences were identified in the text and labelled with codes in the margins. The codes were further compared and grouped together to sub-categories. Finally the sub-categories were compared, regrouped and merged together into more analytical categories.

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### **Fear of taking medication on an empty stomach due to lack of food**

The combination of poverty, lack of food and fear of side effects from medicines was the main obstacle for most patients to start taking ART. Many patients reported having no job, which hindered them from getting money and thus food for themselves and the family. This 33-year-old woman told us about her lack of means to handle a treatment:

I am not saying that I cannot use the treatment. In fact I would want to live longer, but sometimes I do not have a job. Other times I stay for two days without any food. That makes me afraid of using the medication (33-year-old woman).

The patients are informed by the health staff about the importance of good nutrition and to take the drugs with food. Stories about the importance of eating well when taking ART also flourished as general ideas in the community "...these drugs are very strong and you

need to eat well”. When already in a poor nutritional state with seldom enough food to feed the family, many people were afraid they would not have food for themselves in order to manage the ART. They expressed a feeling of not being able to take the medicines on an empty stomach: “If you start and don’t get enough food you will become weak and even die” (38-year-old female).

### **Fear that side effects associated with ART would make one more ill**

The interviewees reported fear of the side effects that would make them too sick to support themselves and their families, as described by this man:

I have not used ART yet. A CD4 count test was done on me and they told me that it was 156 and that I needed to start taking ART. I however got scared of using them when I had heard my colleagues at the support group saying that once one started using the ART, one would get a rash, have diarrhoea and have severe headaches or even vomit. Therefore I thought it would be difficult for me to start using the ART (55-year-old man).

Some respondents had initially been positive to ART, but had been deterred by hearing people in the community talk about side effects, such as this 26-year-old woman:

Later I read and heard about how they affect people and decided not to use them. I decided not to start because I might get too sick and I have no one to help me.

Side effects were seen as one of the major obstacles for patients considering ART. Many who already live on the edge of survival, in bad health, lacking money and food and with heavy responsibilities for their families, were afraid that additional adverse symptoms associated with ART would be too much to cope with. Ideas that ART could “make you infertile, impotent and weak and even kill you” were also prevalent. Many of the respondents, who refused ART, also had a spouse who had experienced side effects of ART in one way or another.

#### **Fear of disclosure and its possible negative repercussions**

According to the interviewees, stigma around HIV/AIDS in Kibera area is strong. Most felt that they had to hide their HIV status to family, friends and especially neighbours, exemplified by this 22-year-old:

They will just be telling other people that I am infected. If I hang my clothes, no one will want to hang theirs close to mine. They will even tell their children not to play with my children. They will abuse my children. I have seen it happen to other people. The people who are HIV positive are not accepted in the society (22-year-old female).

Some of the patients had not disclosed their status to anybody, and the majority had only disclosed to one or two family members. Many respondents felt alone in their disease, lacked social support and had nobody with whom they could share their suffering. Fear of

domestic violence as a consequence of disclosing ones status was brought up as a barrier to disclosure for women as expressed by one 34-year-old woman afraid of being beaten by her husband:

I would not tell him. He might get so shocked he might even harm me. He may also turn against me and tell me that I am the one who brought the disease to him.

MSF required at the time of study that patients disclose their HIV status to at least one person, a so-called treatment buddy, in order to be eligible for ART. Several interviewees expressed their wish to disclose, but could not live openly with their disease out of fear of hurting the family, being rejected by spouse or even thrown out from the family or community. They also felt that awareness about HIV in society must increase for them to be accepted and called for more community campaigns about HIV to end stigma and to raise public awareness. A 32-year-old well-educated man said: "...they have to put more effort in training people, in awareness, in public awareness about HIV and AIDS."

### **Concern for continuity of treatment and care**

Several respondents expressed a feeling of not being ready to take ART and some did not feel motivated since they did not yet feel sick enough. At the clinic, the patients are informed to take their medication every day, not miss a single dose and that they must be prepared to take ART for the rest of their lives. This deterred some from starting ART. A 37-year-old man said: "The fact that I must use these medications on a daily basis is also

something I am not sure I can follow.” Others were worried that they would not be able to continue the treatment if they left Kibera and were therefore hesitant to start, as expressed by this 50-year-old man “If we decide to go to the country side, we do not have anything there.” Several interviewees also mentioned their concern about the future when MSF and other ART-providers might leave.

**Conflicting information from religious leaders and community, and seeking alternative care (e.g. traditional medicine)**

Instead of taking medicines many patients brought up alternative ways of seeking care and hope, mainly from religion and traditional medicine. Many respondents expressed the importance of religion; “One should believe in God. If one does not believe in God, even if one takes medication, it will not be of any use. One has to use both God and the medication.” (34-year old woman), while others’ had experienced or heard stories like this 30-year old woman’s:

...there is a woman who had already started using ART, then she started going to these preachers. When she started going to these preachers, she completely stopped using ART. She believed that she was not sick and wanted the preacher to cast out the evil spirit. She later got very sick and died.

Patients referred to stories of people who had been “saved and they get cured” and reported that religious leaders’ attitude towards condom use or ART was diverse, some

supportive and some not. Traditional medicine is widely used in Kibera and some believe it can cure HIV or that HIV can be transmitted through bad spirits. Even those who expressed disbelief in traditional medicines, would still consider going to a traditional healer since traditional medicines were not associated with side effects and there are less demands attached compared to ART. A major reason though for not going to a traditional healer was high cost, as opposed to the ART that were distributed for free. A 23-year-old woman told us this story:

So in my case, the traditional healer told me that I had crossed over bad water. He told me that if I agreed, he would pray for me. I wanted to go back but he asked for so much money I could not afford to go back (23-year-old female).

### **Illiteracy making patients unable to understand the information given by health workers**

Most patients found the atmosphere at the MSF clinic professional and almost all felt comfortable, even if they wanted to keep their visits secret to others. However, a number of issues were brought up as possible barriers to treatment. The information given was sometimes experienced as incomprehensible or frightening, discouraging patients to start on ART. They also felt the staff had too high expectations and demands on them. One woman described the visit at the clinic as follows:

The only problem is that they do not have time to explain some of the information. Some people do not know how to read, yet they give us some pamphlets to read. You see, that is a bit complicated since you do not know how to read and you are expected to understand what is in the pamphlets before they give you the medication. It would be better if they could explain what is in the pamphlets so that one can understand (35-year-old female).

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Christian Uнге

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We found that the main reasons for HIV positive individuals in the Kibera slum to turn down the offer of free antiretroviral therapy (ART) were lack of food; fear of taking the medication on an empty stomach and fear of side effects that would make them feel sicker. Many also fear disclosure of their HIV status, a requirement for being eligible to the ART programme at the time of this study, something which, in particular for women, may have grave consequences. Illiteracy limiting patients' understanding of the health information provided, concern for discontinuity of care, and conflicting messages from religious leaders and the community were other important reasons of low uptake of ART.

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Information about side effects originated mainly from three sources; the MSF clinics including the patient support groups, the patient's own experiences having witnessed family members or friends suffer from side effects; and thirdly, rumours circulating in the community.

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To increase the uptake of ART and to maintain high adherence, health i

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Feasible tools to assess readiness for treatment are also needed (Crane et al., 2006; Nordqvist, Sodergard, Tully, Sonnerborg, & Lindblad, 2006; Weiss et al., 2003)

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is still a major obstacle for access to ART in Kibera. This

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owever, since the time this study was carried out

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for ART have been removed from

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the MSF program in Kibera after feedback of this study's findings. While there are obvious potential benefits in terms of improved adherence and support, the MSF treatment buddy requirement appeared to be an important barrier to ART uptake for some patients and for women in particular.

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o meet this challenge, health care providers must go

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beyond the traditional healthcare and raise community awareness e.g. through talks at local churches and schools

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. Health Care to people living with HIV and AIDS (PLWHA) should be expanded and go beyond the traditional (paternalistic) patient-doctor encounter.

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ould be considered essential components of ART programs in resource-poor contexts. To meet the growing needs given the lack of trained human resources, task shifting using

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patients, relatives and communities for

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should take over some of the tasks currently carried out by health care workers, such as

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treatment education, early referral mechanisms and/or defaulter tracing appears necessary.

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- Bangsberg, D. R. (2006). Monitoring adherence to HIV antiretroviral therapy in routine clinical practice: The past, the present, and the future. *AIDS Behav*, 10(3), 249-251.**
- Calleja, J. M., Marum, L. H., Carcamo, C. P., Kaetano, L., Muttunga, J., & Way, A. (2005). Lessons learned in the conduct, validation, and interpretation of national population based HIV surveys. *Aids*, 19 Suppl 2, S9-S17.**
- Central Bureau of Statistic Nairobi, K. (2003). Kenya Demographic and Health Survey 2003. Retrieved 7 September 2006, from <http://www.afronets.org/files/KenyaDHS2003.pdf>**
- Chakaya, J. M., Meme, H., Kwamanga, D., Githui, W. A., Onyango-Ouma, W. O., Gicheha, C., et al. (2005). Planning for PPM-DOTS implementation in urban slums in Kenya: knowledge, attitude and practices of private health care providers in Kibera slum, Nairobi. *Int J Tuberc Lung Dis*, 9(4), 403-408.**
- Chemuliti, J. K., Gathura, P. B., Kyule, M. M., & Njeruh, F. M. (2002). Bacteriological qualities of indoor and out-door drinking water in Kibera sub-location of Nairobi, Kenya. *East Afr Med J*, 79(5), 271-273.**
- Crane, J. T., Kawuma, A., Oyugi, J. H., Byakika, J. T., Moss, A., Bourgois, P., et al. (2006). The price of adherence: qualitative findings from HIV positive individuals purchasing fixed-dose combination generic HIV antiretroviral therapy in Kampala, Uganda. *AIDS Behav*, 10(4), 437-442.**
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 24(2), 105-112.**
- Gulis, G. (2004). Health status of people of slums in Nairobi, Kenya. *Environmental research*(96), 219-227.**

- Homsy, J., King, R., Balaba, D., & Kabatesi, D. (2004). Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *Aids*, *18*(12), 1723-1725.
- Kumarasamy, N., Safren, S. A., Raminani, S. R., Pickard, R., James, R., Krishnan, A. K., et al. (2005). Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: a qualitative study. *AIDS Patient Care STDS*, *19*(8), 526-537.
- Mills, E., Cooper, C., & Kanfer, I. (2005). Traditional African medicine in the treatment of HIV. *Lancet Infect Dis*, *5*(8), 465-467.
- Morris, K. (2001). Treating HIV in South Africa--a tale of two systems. *Lancet*, *357*(9263), 1190.
- Munk, K. (1997). Traditional healers, traditional hospitals and HIV / AIDS: a case study in KwaZulu-Natal. *AIDS Anal Afr*, *7*(6), 10-12.
- Nordqvist, O., Sodergard, B., Tully, M. P., Sonnerborg, A., & Lindblad, A. K. (2006). Assessing and achieving readiness to initiate HIV medication. *Patient Educ Couns*, *62*(1), 21-30.
- Remien, R. H., Hirky, A. E., Johnson, M. O., Weinhardt, L. S., Whittier, D., & Le, G. M. (2003). Adherence to medication treatment: a qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities. *AIDS Behav*, *7*(1), 61-72.
- Siegel, K., & Schrimshaw, E. W. (2005). Stress, appraisal, and coping: a comparison of HIV-infected women in the pre-HAART and HAART eras. *J Psychosom Res*, *58*(3), 225-233.
- Stenson, A. L., Charalambous, S., Dwaadwa, T., Pemba, L., Du Toit, J. D., Baggaley, R., et al. (2005). Evaluation of antiretroviral therapy (ART)-related counselling in a workplace-based ART implementation programme, South Africa. *AIDS Care*, *17*(8), 949-957.
- Stevens, W., Kaye, S., & Corrah, T. (2004). Antiretroviral therapy in Africa. *Bmj*, *328*(7434), 280-282.
- Stringer, J. S., Zulu, I., Levy, J., Stringer, E. M., Mwangi, A., Chi, B. H., et al. (2006). Rapid scale-up of antiretroviral therapy at primary care sites in Zambia: feasibility and early outcomes. *Jama*, *296*(7), 782-793.
- Weiss, L., French, T., Finkelstein, R., Waters, M., Mukherjee, R., & Agins, B. (2003). HIV-related knowledge and adherence to HAART. *AIDS Care*, *15*(5), 673-679.
- WHO. (2002, 2002). Traditional medicine-Growing needs and Potential. Retrieved September 7, 2006, from [http://whqlibdoc.who.int/hq/2002/WHO\\_EDM\\_2002.4.pdf](http://whqlibdoc.who.int/hq/2002/WHO_EDM_2002.4.pdf)
- WHO. (2004). Epidemiological fact sheets on HIV/AIDS and SEXUALLY TRANSMITTED INFECTIONS: Kenya. Retrieved September 7, 2006, from [http://www.who.int/GlobalAtlas/predefinedReports/EFS2004/EFS\\_PDFs/EF\\_S2004\\_KE.pdf](http://www.who.int/GlobalAtlas/predefinedReports/EFS2004/EFS_PDFs/EF_S2004_KE.pdf)
- WHO. (2005, 2005). "3 by 5" country profile on treatment scale-up, December 2005. Retrieved September 7, 2006, from [http://www.who.int/hiv/HIVCP\\_KEN.pdf](http://www.who.int/hiv/HIVCP_KEN.pdf)

Zachariah, R., Nkhoma, W., Harries, A. D., Arendt, V., Chantulo, A., Spielmann, M. P., et al. (2002). Health seeking and sexual behaviour in patients with sexually transmitted infections: the importance of traditional healers in Thyolo, Malawi. *Sex Transm Infect*, 78(2), 127-129.

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Table 1. Socio-demographic facts.

Pat number	Sex	Age	Ethnic group	Disclosed to at least one person	Status
1	m	27	Luo	y	Married
2	m	26	Luo	y	Married
3	f	33	Kikuyu	y	Single
4	f	38	Luo	y	Separated
5	f	36	Luo	y	Widow
6	f	36	Kisii	n	Single
7	m	39	Kamba	y	Married
8	m	50	Luhya	y	Married
9	m	35	Luo	n	Married
10	f	46	Luo	n	Widow
11	f	34	Luhya	n	Widow
12	f	32	Kamba	y	Separated
13	m	37	Kamba	y	Married
14	f	24	Kamba	y	Married
15	f	24	Luo	y	Married
16	f	27	Luo	y	Married
17	f	38	Luo	y	Widow
18	m	29	Kalenjini	y	Single
19	f	26	Kikuyu	y	Single
20	m	32	Kisii	y	Separated
21	f	28	Luhya	y	Separated
22	m	55	Kisii	y	Married
23	f	23	Luo	n	Single
24	f	35	Luo	y	Widow
25	f	40	Kamba	y	Married
26	f	25	Kamba	y	Married

Table 2. Categories and quotes

Category	Quote
Fear of taking medication on an	<i>I am not saying that I cannot use the treatment. In fact I would want to live longer, but sometimes I do not have a job. Other</i>

empty stomach due to lack of food	<i>times I stay for two days without any food. That makes me afraid of using the medication (33-year-old woman)</i>
Fear that side effects associated with ART would make one more ill	<i>...I had heard my colleagues at the support group saying that once one started using the ART, one would get a rash, have diarrhoea and have severe headaches or even vomit. Therefore I thought it would be difficult for me to start using the ART (55-year-old man)</i>
Fear of disclosure and its possible negative repercussions	<i>They will even tell their children not to play with my children. They will abuse my children. I have seen it happen to other people. The people who are HIV positive are not accepted in the society (22-year-old female)</i>
Concern for continuity of treatment and care	<i>If we decide to go to the country side, we do not have anything there (50-year old man)</i>
Conflicting information from religious leaders and community, and seeking alternative care (e.g. traditional medicine)	<i>One should believe in God. If one does not believe in God, even if one takes medication, it will not be of any use. One has to use both God and the medication (34-year old woman)</i>
Illiteracy making patients unable to understand the information given by health workers	<i>The only problem is that they do not have time to explain some of the information. Some people do not know how to read, yet they give us some pamphlets to read...(35-year-old female).</i>

Table 1. Socio-demographic facts.

Pat number	Sex	Age	Ethnic group	Disclosed to at least one person	Status
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6	f	36	Kisii	n	Single
7	m	39	Kamba	y	Married
8	m	50	Luhya	y	Married
9	m	35	Luo	n	Married
10	f	46	Luo	n	Widow
11	f	34	Luhya	n	Widow
12	f	32	Kamba	y	Separated
13	m	37	Kamba	y	Married
14	f	24	Kamba	y	Married
15	f	24	Luo	y	Married
16	f	27	Luo	y	Married
17	f	38	Luo	y	Widow
18	m	29	Kalenjini	y	Single
19	f	26	Kikuyu	y	Single
20	m	32	Kisii	y	Separated
21	f	28	Luhya	y	Separated
22	m	55	Kisii	y	Married
23	f	23	Luo	n	Single
24	f	35	Luo	y	Widow
25	f	40	Kamba	y	Married
26	f	25	Kamba	y	Married

Table 2. Categories and quotes

Category	Quote
Fear of taking medication on an empty stomach due to lack of food	<i>I am not saying that I cannot use the treatment. In fact I would want to live longer, but sometimes I do not have a job. Other times I stay for two days without any food. That makes me afraid of using the medication (33-year-old woman)</i>
Fear that side effects associated with ART would make one more ill	<i>...I had heard my colleagues at the support group saying that once one started using the ART, one would get a rash, have diarrhoea and have severe headaches or even vomit. Therefore I thought it would be difficult for me to start using the ART (55-year-old man)</i>
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Illiteracy making patients unable to understand the information given by health workers	<i>The only problem is that they do not have time to explain some of the information. Some people do not know how to read, yet they give us some pamphlets to read...(35-year-old female).</i>