Evaluation of Antiretroviral Therapy among HIV-patients in Dar es-Salaam, Tanzania

- Identifying areas critical for adherence

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Abstract

Background: The United Republic of Tanzania belongs to the Sub-Saharan region of Africa, which is the most affected area in the world by the HIV-epidemic. Tanzania has today a prevalence of HIV among adults of 5.8 percent in a population of about 38 million inhabitants which adds up to 2.2 million infected people. The incidence rate seems to be declining and great efforts have been made to prevent the spread of the disease in the country. Earlier studies have shown a good compliance to antiretroviral therapy (ART) in Tanzania despite limited resources.

Objective: The project’s main purpose was to evaluate adherence and risk factors related to HIV and antiretroviral treatment at the largest government owned hospital in Tanzania, namely the Muhimbili National hospital in Dar es-Salaam. We mainly looked at factors contributing to a good adherence, side-effects, sexual risk behaviour, and tried to estimate the greatest obstacles the patients encountered in order to follow treatment, with the goal to find areas in need of improvement from the patient’s point of view.

Method: The study conducted at the HIV clinic of the Muhimbili National Hospital was based on a self reported qualitative and quantitative questionnaire as well as information from the patient files. Adult patients that had been enrolled in an ART program for more than two years were met with at the time for their clinical visit. They were given a questionnaire to fill containing questions about their compliance, side effects, obstacles, socio-economical status, and knowledge about HIV, how they were infected, sexual behaviour and health status. From the patients files we collected information about their treatment such as CD4+ levels, adverse reactions, adherence assessment and Karnofsky score before starting treatment. A few semi-structured interviews were made with patients in order to receive a deeper understanding for the patients and their situation.

Results: The questionnaire results were analyzed for a total number of 202 patients and 182 patient files were collected for information. We found a high compliance (>95%) to ART among the patients both self-assessed and recorded in patient files. It was also confirmed by the average increase in CD4+ levels of over 50%. A great improvement regarding general health status was reported due to ART. Knowledge of HIV was limited regarding the spread of the disease (less than 80% knew that HIV is spread through intercourse without a condom) and more than fifty percent of the patients thought they could not transmit the virus while being on ART. Forty-five percent of the men and 48% of the women had peripheral neuropathy (PNP). The greatest self-reported obstacles were too little information about the treatment, discrimination and logistical problems regarding hospital visits. Significant differences were observed between the sexes regarding employment and marital status.

Conclusion: Adherence to ART was high for patients treated on average 3 years. However, further studies are required regarding drop-outs from the clinic. More thorough education of the patients regarding HIV, ART, and sexual risk behaviour is needed. Fear of discrimination is a major factor limiting disclosure and also adherence. Better opening hours and fewer visits to improve the social situation of the patients is needed according to the patients. Patients have reported to have a much better health status since starting with ART.
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**Introduction**

Tanzania is one of the countries of the Sub-Saharan region of Africa most severely affected by the HIV-epidemic and has today a prevalence of HIV among adults on 5.8 percent\(^1\) in a population of about 38 million inhabitants\(^1\) which adds up to 2.2 million infected people. In 2003 the prevalence was 7 percent\(^1\). The incidence rate is declining and great efforts have been made to prevent the spread of the disease in the country\(^2\). The national response has shifted from a focus merely on interventions aimed at prevention towards one of care and treatment as well.

The epidemic has a devastating effect on social- and economical development in a population where the majority is living under the poverty limit of 1 USD per day. It is a disease which affects people in their most vital time of life and therefore the productivity in the country declines. Between 1983 and 1994 the annual Gross Domestic Product (GDP) declined from USD 268 to USD 91\(^3\). A major reason for this decline is thought to be the HIV-epidemic even though other factors play a role as well.

Since 2004, the Government in collaboration with partners initiated a care and treatment program under the National Aids Control Programme (NACP). The use of highly active antiretroviral therapies (HAART) is one of the interventions for preventing the spread of the disease. Between the years of 2003 and 2006 the number of patients on HAART has grown from 100,000 to 1 million\(^3\). In 2009 the cumulative number is 287,000. The antiretroviral treatment in Tanzania is free since 2005. However, the scaling up of ART is a challenge. In 2008 only 22.2% of HIV-infected patients that qualified for treatment were enrolled in an ART program\(^3\). More effort is also needed to promote voluntary counselling and testing. The President His Excellency Dr Jakaya Kikwete recently launched a national campaign for voluntary HIV/AIDS testing in Dar es-Salaam\(^4\).

Dar es-Salaam, being the largest city in Tanzania, also holds the largest hospital in the country called the Muhimbili National Hospital (MNH). Data shows that twice as many HIV-positive people live in the urban areas as in the rural areas\(^5\). The ART started at this hospital in 2003 and has its own HIV-clinic that takes care of 6,543 patients living with HIV. Four doctors per day are working at the clinic and there are about 120-150 patients per day visiting the clinic for their monthly control and refill of antiretroviral medicines. Most of the patients live in Dar or in an area close to the city but patients are also referred to MNH from lower health facilities when they have complications that need more specialized attention, and are then sent back to their CTC’s once they have been helped.

To maintain long-term health benefit of the ART and to avoid development of drug resistance, adherence to ART is critical. Monitoring adherence is essential because it is likely to decrease over time\(^7\). Typical adherence rates for all kinds of medications prescribed over long periods of time are approximately 50-75%\(^6\). One way to define adherence may be as the extent to which a patient takes a medication in the way intended by a health care provider\(^8\).

This disease is truly a problem that affects all parts of life and society. It needs to be target at many levels and the medical approach is only one of them. Acceptance of HIV-positive people in society, change of sexual behaviour, empowerment of women, education in general as well as information about HIV and treatment are just as important. In this report we wanted to lift some of these different issues and their correlation to adherence to ART.
Objective

The project’s main target was to evaluate adherence to antiretroviral treatment (ART) at the largest government-owned hospital in Tanzania, namely the Muhimbili National Hospital in Dar es-Salaam. The aim of the study was to try and identify areas of success as well as obstacles from the patients’ point of view with the hope of contributing to a good treatment. We also wanted to get an insight into the daily work at the HIV clinic and to get an understanding of the patients’ situations living with HIV and antiretroviral treatment.

The project aims were:
- To evaluate adherence to antiretroviral treatment by patients treated for at least two years.
- To identify and understand obstacles encountered by the patients in order to follow treatment.
- To evaluate side-effects caused by the different antiretroviral drugs.
- To estimate knowledge about HIV transmission, ART, and general knowledge of HIV.
- To study sexual risk behaviour after HIV diagnosis and during treatment.
- To try to evaluate if the patients’ economical status had changed in relation to HIV-diagnosis and treatment.
- To evaluate differences between men and women regarding side-effects, knowledge and social status.

Methods

Study settings
The study was performed during June - August 2009 at the Muhimbili National Hospital (MNH). Patients were recruited into the study while waiting for their doctor’s visit at the HIV Clinic. They were given verbal and written information about the project and could then agree to participate by filling in a consent form.

The clinic received HIV-patients every day during the week coming for care including provision of medicine. Patients initiated to treatment were given counseling about the ART, health education, information about HIV, a clinical examination and CD4+ count. During treatment patients visited the clinic once per month to get a refill, a clinical examination and to report possible adverse effects.

The patients’ clinical status was classified through the WHO clinical stages 1-4, and Karnofsky score. Viral load was seldom measured at the clinic. Treatment with ART was initiated if the CD4+ count was under 200 cells/mm³ or between 200-350 cells/mm³ and WHO clinical stage 3 or clinical stage 4 regardless of CD4+ count.

It was recommended to treat patients with a combination of drugs consisting of 2 NRTI (Nucleoside Reverse Transcriptase Inhibitors) + 1 NNRTI (Non-Nucleoside Reverse Transcriptase Inhibitors) or 2 NRTI + 1 PI (Protease Inhibitors) or 3 NRTIs. Examples of antiretroviral medicines used were NRTIs stavudine, ziduvudine, lamivudine and NNRTIs nevirapine and efavirenz (Triomune and Combivir).

Study design
This cross-sectional study was based on a self-reported semi-structured qualitative and quantitative questionnaire. From the patients’ files data was collected regarding type of antiretroviral medicine,
CD4+ count, side effects, adherence assessment, WHO clinical stage and Karnofsky score. Twenty open interviews were performed with randomly selected patients equally divided between men and women in order to receive a deeper understanding for the patients’ situations. Each patient was given a number to match with the questionnaire and the file of the patient. Investigators were not blinded to the patients’ answers or to their files.

Patients were guaranteed that their answers would be handled confidentially. The patients did not write their names on the questionnaire, only on the consent. This list was stored in a way that no one else than the investigators of the project had access to it. After the end of the project, the list was destroyed.

Patients
Patients that had been on ART for more than two years were selected randomly by nurses in the clinic in relation to their clinical visit.

Inclusion criteria:
1) Age over 18
2) HIV-positive
3) Received antiretroviral treatment during at least two years
4) Consent to participate by signature

Patients were excluded if they had been on ART for less than two years and if they did not agree to sign the consent. Questionnaires were handed out to 202 patients. Eight patients decided not to participate by not handing in their questionnaires.

Detailed description of the questionnaire
A questionnaire containing 51 questions regarding socio-economic status, educational level, basic knowledge about HIV and antiretroviral treatment, cause of infection, sexual behaviour and health status were handed out to patients agreeing to participate. Furthermore, we asked about adherence to treatment, side-effects to medication, obstacles patients encountered in order to follow treatment and expenses related to treatment.

The questionnaire was translated into Kiswahili by an interpreter in Sweden and was revised by our supervisor Dr Bakari at the Muhimbili University of Health and Allied Sciences (MUHAS). A nurse at the clinic worked as our interpreter at several occasions since the questionnaire had to be read out aloud to some patients due to poor vision and illiteracy.

Socio-economic status
Gender, education, age, employment, and marital status, were included in this topic. These questions were aimed to see if possible correlations between adherence and knowledge of HIV could be correlated with differences in socio-economic status.

Adherence
To estimate adherence, a question regarding numbers of missed tablets during the last month was included. Reasons for missing tablets were multi-optional questions. The aim was to identify obstacles in order to follow treatment that in the end can lead to finding solutions to minimize these reasons.

Subjective health
Quality of life before and during ART was appreciated using a scale of 1 to 5, where “1” meaning a low health status and “5” meaning a high health status. Positive and negative effects due to treatment
with ART were included to appreciate the effects of ART from different aspects and to see if these factors could have an influence on adherence.

**HIV testing**
These questions were included to evaluate why the patients were tested for HIV, and in what phase of the HIV-infection they were tested. Questions regarding tests of the partner and children were also included.

**HIV and ART knowledge**
Questions regarding knowledge about HIV-transmission and effects of ART were used to estimate if there was a satisfying level of knowledge among the patients and if the information given by the clinic was sufficient or not.

**Obstacles to follow treatment**
We intended to find out if specific obstacles related to treatment could be found that limited the patients´ ability to follow the treatment as intended. This could inspire the search for new methods that can help patients improve their adherence.

**Sexual risk behaviour**
Questions regarding condom use, STIs and HIV-status of the partner were collected to investigate the level of sexual risk behaviour.

**Disclosure**
Questions about disclosure were included to analyse the difficulties the patients encounter in the social context and to estimate the level of discrimination. It is an important factor correlating to risk behaviour and adherence to treatment as well.

**Economical situation**
Questions about the patients´ economical situation before enrolment in the ART program compared to after enrolment as well as capacity to work at the present compared to before the start with ART were included to try and analyse the correlation between health status and economical welfare. Patients also reported the number of dependants in their household.

**Patient files and patient cards**
The CD4+ count before starting treatment and during treatment was noted for each patient as well as side-effects, Karnofsky score, WHO clinical stage, number of missed doses, adherence assessment, type of antiretroviral medicine and reason for change of ART regimen. Information from 18 Patient files was excluded due to missing files.

**Statistics**
The data was analyzed in Microsoft Excel for numerical calculations and for graphical presentation. Crossover analyses were made regarding differences between the sexes. The results were considered significant if p <0.05 using a confidence interval of 95%. Colton’s Statistics.

**Ethical clearance**
The study was approved by the Ethics Committee at the Muhimbili University of Health and Allied Sciences.
Results and Discussion

Demographic data

Religious belonging
Altogether 195 people answered this question of which 118 were women and 56 were men. Sixty percent of the women and 52% of the men were of Christian belonging. The remaining patients were of Islamic belonging.

Region
Most of the patients visiting this clinic were citizens of Dar es Salaam (95%, N=187). Therefore it was difficult to analyze any significant differences due to regional differences.

Employment

As presented in figure 1, only 39 percent of the patients were employed. This means that 60 percent of the patients did not have a steady income. A difference regarding employment status and type of employment was observed between men and women. Only 23 percent of the women were employed compared to 40 percent of the men. Women were more often self-employed (29%), than men (22%). Thirty-four percent of the women, including housewives (22%), were unemployed, compared to only 2 percent of the men.

A similar tendency regarding unemployment was shown in a study made in Ilembula where 22 % of the women were unemployed and 14 percent of the men. According to the international labor organization there is a difference between unemployment amongst men and women in Tanzania. Of 892 people included in their study the unemployment rate was 2.1 among men and 5.8 among women and the employment rate 80.5 percent amongst men and 76 percent amongst women. Compared to this study the women on ART in our study had a higher level of unemployment compared to the general population in Tanzania. This difference was not seen between men on ART and the general male population in Tanzania.
It is important to take into account that the 21 percent of the patients that ticked the box single/never married could imply that the patient had a boyfriend (23%) or a girlfriend (20%) but was not yet married. It is therefore difficult to separate this group from the group consisting of cohabiting couples (not married). Thirty-five percent of the women were married compared to 61% of the men (p<0.05). Ten percent of the women were divorced and 4 percent of the men. There was also a great amount of widows and widowers (24%), and a significant (p<0.05) higher amount of women that had lost their spouse (30%) compared to men (12%).

In a study conducted in Ilembula, 50 percent of HIV positive women were widows compared to only 7 percent of HIV positive men. During the interviews many female patients said they had lost their partner due to HIV. It is therefore possible that men receive the virus in an earlier stage in life. This might be due to the fact that many women were infected by their husbands. Many women also said that their partner had divorced them after finding out that they were HIV positive. That could possibly explain the higher amount of divorces among the women. According to the WHO, 27 percent of widowed Tanzanian women are HIV positive, 2 percent of the unmarried women and 6 percent of women who are married or cohabiting. The risk of being HIV positive has also shown to be significantly higher amongst women who are not married, cohabiting women, single women, divorced women or widowed women. This study consist with our findings that widowed Tanzanian women are often HIV-positive.
Children

Eight percent of the patients did not have any children, and 39 percent had more than two children. The average was 2.5 children per patient.

This result can be compared to a WHO report on Tanzania where the average was 5.2 children per person (2007)\(^1\). People receiving ART are given birth control medication to make it possible to minimize unintended pregnancies among HIV positive\(^3\). Like many other diseases HIV lower the fertility and also make it more difficult to find a partner. These might be important explanations why people on HIV have fewer children.

**HIV positive children**

Eleven patients, (7%), claimed their children were HIV positive. It is however possible that the number was greater since many children were not tested according to the patients\(^12\). All pregnant women in Tanzania are supposed to receive an HIV test during their pregnancy, and should be treated with ARVs during their pregnancy\(^6\).

**Age**

The average age among our patients was 42.5 years, median 42 years. The median age was 40 (mean 40.1) years for women and 47 (mean 46.8) years for men. The number of patients answering this question was 113 women and 54 men and 7 patients with an unknown gender.

The average age in Tanzania in general is 18 years and the life expectancy is around 50-51 years for both sexes\(^1\). Our patients differed highly from these numbers where the average age was 42 years. The fact that our patient group is older might be due to the fact that the number of new infections is decreasing in Tanzania. This has been observed during the last years with a fewer number of newly infected young people\(^3\). Another explanation is that the risk of being infected with HIV increases significantly with age and is rare before the sexual debut in the teenage\(^13\). In these ages a great part of children get infected by mother-to-child transmission\(^14\).
Only 5 percent had finished postsecondary school and 60 percent had not reached secondary school. Five percent had never been to school. There was a greater amount of women having reached above secondary school (56%) compared to men (41%). Regarding university studies, 7 percent of the men had reached that level compared to 2 percent of the women. No significant differences were found between the sexes regarding educational level.

According to the WHO, 97 percent of the women and 98 percent of the men in Tanzania enroll in primary school. This is definitely comparable to our results. In a study performed in Ilembula in 2008, 18 percent of the women and 19 percent of the men had never been to school. This is probably due to the fact that there were less possibilities of schooling at the country side than in the greater cities. Or does it show that there was a greater risk of being exposed to HIV in the great city Dar regardless of educational level? In Tanzania the HIV prevalence is higher among women (7.7%) compared to men (6.3%). The HIV prevalence is significantly higher in urban areas (11%) than in rural areas (5%). It has also been shown that a low education is a risk for HIV; and also a low educational status of the partner.

Ability to read
Thirty percent of the women (N=121) and 23 percent of the men (N=56) needed help to fill in the questionnaire. Some of the patients that could read, had a poor vision. This question could therefore not work as a good measurement regarding analphabetism. The adult literacy rate is 69.4 percent in Tanzania according to the WHO (2009), but some studies have shown even a higher literacy rate.
Sex
Most of the patients visiting the clinic were women. Therefore most of the participating patients in our study were women, (65.6%, N=127) compared to 30 percent (N=58) men. A small group (3.8%, N= 7) did not report their gender. The fact that there were more women in the clinic could be due to various factors such as the testing of women during pregnancy, and that many men do not test for HIV until having symptoms. The fact that many (42%) women in their youth receive gifts or money for sexual favors and therefore are at a high risk for HIV infection might contribute to this difference. Many women that go into prostitution also receive a better payment if they do not use a condom which increases the risk even further.

Transport
Most of the patients (88%), took the bus to reach the hospital. The average time it took to the hospital was 2 hours, median 1.5 hours. The bus fare is about 250-500 Tanzanian shilling per way inside Dar es-Salaam (about 3 SEK). A great part (82.4 %) of the population lives on less than one US dollar per (ca 1200 T shilling) day in Tanzania. Due to these facts, it is understandable that the patients consider the frequent visits to the clinic as an obstacle in order to follow their ART.

HIV testing

<table>
<thead>
<tr>
<th>Why did you test for HIV?</th>
<th>women N=124</th>
<th>men N=55</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other reason:</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td>I had symptoms of HIV infection</td>
<td>29</td>
<td>36</td>
</tr>
<tr>
<td>I was informed about the opportunity to get tested for HIV</td>
<td>24</td>
<td>31</td>
</tr>
<tr>
<td>I was pregnant</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Worried that my previous partner was infected with HIV</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Worried that my actual partner was infected with HIV</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>My child was HIV positive</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>My partner was HIV positive</td>
<td>13</td>
<td>27</td>
</tr>
<tr>
<td>I was ill</td>
<td>61</td>
<td>66</td>
</tr>
<tr>
<td>I was getting married</td>
<td>11</td>
<td>13</td>
</tr>
</tbody>
</table>

Fig 5. Reasons for HIV-testing, in percent.

The most common reason for HIV-testing were being ill or having symptoms of HIV. Secondly was the information about getting a test and having an HIV positive partner. No significant differences were obtained between the sexes except for the reason of being pregnant. This means that the disease most often had reached an advanced state before it was discovered.
A similar tendency was shown at the country-side in a study conducted in Ilembula where 86 percent of the men and 63 percent of the women were tested due to HIV symptoms. According to a WHO report in 2009, 37.2 percent of the men and 26.5 percent of the women have never conducted an HIV test. But these numbers seem to have changed during the later years and it seems to be a much greater part of women being tested since the HIV testing during pregnancy were recommended. In a vaccine study including HIV testing, made on policemen in Dar es-Salaam, the fear of knowing their HIV status (54.6%, N=132), was the most frequent reason to drop out from the study. This could support our findings of patients not testing for HIV until a sign of symptoms because of the fear of a positive test makes many people prefer not knowing their status.

**HIV-testing of the partner**

![Graph](image1.png)

**Fig 6.** Patients with a partner tested for HIV, in percent. Men N=54, women N=72.

![Graph](image2.png)

**Fig 7.** Patients that live with an HIV-positive partner, in percent.
A slightly higher percent amongst the men (22%) compared to women (17%) had partners tested for HIV. Several women claimed during the interviews that their partners did not want to get tested for HIV. One sixth of the patients were without partners (25 patients). Almost one third (32%) of the patients whose partner was tested, had a partner that was tested positive for HIV. Forty-four percent did not know the result of their partner’s testing. Regarding cohabiting partners 36 percent of the patients claimed they had a HIV positive partner. There was a significant difference (p<0.05) between women (27%) and men (54%) having a positive HIV partner. This could be due to the fact that women more often test themselves then men.

Many female patients were afraid to disclose their HIV status to their partner because of fear of being divorced from\textsuperscript{12}. This is probably due to the fact that the men more often had a steady income. Therefor there were signs indicating that there was a great number of men living with HIV-positive women without knowing it or they found out during the pregnancy of their partner.

\textbf{Knowledge of HIV}

![Knowledge about ART](image)

\textbf{Fig 8. Knowledge about ART, in percent.}

Sixty-five percent of the men and 64 percent of the women thought they could not transmit the virus while being on ART. Only 12 percent of the men and 19 percent of the women thought they were less contagious due to treatment with ARVs. This is a very important fact to put a lot of effort into since there is a high risk that the spreading of the virus will not be controlled, if this factor does not improve. No significant difference was seen between the sexes.

Eighty-two percent of the patients thought that losing effect because of resistant virus would happen if they did not continue their ART and 12 percent of the patients thought nothing would happen, if they stopped their medication. There was a tendency observed between women and men, where 93 percent (N=119) of the women compared to 78% (N=54) of the men thought losing effect because of resistant virus would happen.
Seven percent of the patients had no idea of how HIV was transmitted. Less than 80% knew that HIV is transmitted through sexual intercourse without a condom and through blood transfusion. Only half of the patients knew that HIV can spread from mother to child during pregnancy. Even fewer patients knew that HIV is spread through oral sex, and through breastfeeding. This is something that has to be improved at the clinic. There was also a tendency towards better knowledge among women regarding HIV spread through breastfeeding (women 46 %, men 33%), blood (women 73%, men 56%) and mother to child during pregnancy (women 60%, men 44%). No significant difference was seen between the genders.

In general in Tanzania males between 15-24 years old with correct knowledge of the HIV Virus is 40 % compared to 45% among females¹. Another study conducted at Muhimbili Hospital on drivers and conductors in Dar es-Salaam showed that more than 80 % of the participants knew that condom was the most common method to prevent HIV. More than 90 % of the participants had received this information from the media²⁰. It is therefore a low number of our patients with a correct knowledge of HIV, due to the fact that they are frequently visiting an HIV clinic where they are given information when they start the treatment. Compared to the study in Illembula, 96 % of the men and 84% of the women were aware that HIV is transmitted when having sex without a condom⁸. On the other hand patients’ knowledge about oral sex was higher in our study.
Adherence

Fig 10. Amount of ART tablets ingested per day, in percent.

The medium number of ARV tablets taken per day was 2.75 per person. Twenty-seven percent have missed at least one pill during the last four weeks and 15% claim that they have difficulties taking their tablets as they have been recommended by the health staff.

Fig 11. Number of missed tablets, in percent.

Only 10 patients (6%) claimed they had missed more than 3 tablets during the last four weeks. This shows that our patients have a good compliance, 34 patients (21%) had missed between 1-2 tablets during this period of time. No significant differences were observed between men and women. Another study conducted at the Muhimibili Hospital has shown that only 0.7% shown less than 95% adherence. In that study 16.4% were lost to follow up. The clinic has a responsibility to follow up the patients in order to keep track of compliance. This is done by having the patients come on regular
follow-ups and refill of medication each month. The result shows that this clinic is doing a good job in following up the patients.

It has been demonstrated that social responsibility contributes to a better compliance. Many patients receive help from family and friends, and these helpers expect to see full compliance. The adherence in Sub Saharan Africa exceeds the level of adherence seen in North America, even though these patients face a more difficult task in following their medication.

If you ever miss to take your tablets, what is your reason?

<table>
<thead>
<tr>
<th>Reason</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>other</td>
<td>25</td>
</tr>
<tr>
<td>felt the drug was harmful</td>
<td>2</td>
</tr>
<tr>
<td>did not want other noticing me taking the medication</td>
<td>11</td>
</tr>
<tr>
<td>felt better and therefore didn't need to take the tablets</td>
<td>3</td>
</tr>
<tr>
<td>I accidentally took the wrong tablet</td>
<td>2</td>
</tr>
<tr>
<td>felt sad or depressed</td>
<td>5</td>
</tr>
<tr>
<td>wanted to avoid side effects</td>
<td>25</td>
</tr>
<tr>
<td>was asleep and therefore forgot the medicine</td>
<td>5</td>
</tr>
<tr>
<td>had a change in daily routine</td>
<td>25</td>
</tr>
<tr>
<td>share tablets with others</td>
<td>1</td>
</tr>
<tr>
<td>could not attend the clinic</td>
<td>5</td>
</tr>
<tr>
<td>ran out of tablets</td>
<td>25</td>
</tr>
<tr>
<td>simply forgot</td>
<td>25</td>
</tr>
</tbody>
</table>

Fig 12. Reasons for not taking tablets, in percent.

This question had few patients answered. Probably they could not understand the question, since it was placed directly after the question regarding if they had missed taking any tablets during the last four weeks, most patients thought they should not answer this question if they had not missed any tablets within four weeks. Among these, most patients regarded the most important reasons were simply forgot to take my tablets, ran out of tablets and wanting to avoid ARV induced side effects. On the question regarding if the patients have difficulties taking their medication at the specific times as directed by the doctor, 28 % (N=166) answered, yes. This problem has been solved for some patients by the use of a calendar that has to be ticked every time the patient takes the tablets and it has been successful. In South Africa they are using sms to remind the patients to take their pills. Since the use of mobile phones are so widely used in Tanzania this could be worth trying at the Muhimbili Hospital as well. Only 1% claimed to share tablets with others, a low number which is very good. Our results differed from the results obtained from the study in Ilembula where 21% forgot to take their tablets.
15% ran out of tablets, 13% trying to avoid side-effects where our study showed higher percentage in all three alternatives, see figure above⁸.

**Positive effects from ART**

Fig 13. Reported positive effects from ART, in percent.

The most reported positive effect was having more energy. A tendency was observed between the sexes (men 96% and women 84%) reporting having more energy, increased weight (men 60%, women 46%). There was also a tendency regarding feeling happier and having an increased appetite amongst women. This was better compared to the Ilembula study where only 0 percent of the women and 6 percent of the men that had more interest in sex⁸.
Almost one third of the patients claimed they had no obstacles in following the treatment. The most common obstacles were to visit the clinic which might include transportation problems to and from the clinic. There was a significant difference between men (82%) and women (29%) receiving too little information about the treatment. This factor is important to take into account regarding prevention and compliance. In Ilembula a slightly higher percentage of the men wanted more information about the treatment\textsuperscript{8,22}. In all three studies, men wanted more information but it was only in our study the difference was significant.

Other problems associated to the treatment were the economical cost related to it and to take time off from their daily activities, side effects from ARVs and to remember to take the tablets regularly. Twenty-five percent of the patients claimed that discrimination was an important obstacle. This can also be associated to the obstacle of taking time of daily activities to be able to visit the clinic. Thirty-four percent of the patients said that the development of stigmata was a great obstacle to them. This was more often reported by women than by men. As many as 38 percent thought they had to visit the clinic too often and 43% thought the opening hours of the clinic was a great problem. Many patients said during the interviews that it was difficult for them to take time off from their work to visit the clinic. It was also difficult for them to tell their employer that they had to visit the clinic, since they were afraid of losing their work, due to being HIV positive.
It has been shown in other studies that many patients express a desire to have the clinic more close to their homes\textsuperscript{24}. Other studies in Dar es-Salaam have shown that the need of improving infrastructure, more trained health personnel and an improved situation regarding counseling will be necessary to improve the situation for patients under ART\textsuperscript{25}.

**Interruption of medication**

Among the patients answering the questionnaire, 10 percent had interrupted their HIV medication. As many did not answer this question, 13 percent of the women answered that they had interrupted their HIV treatment compared to 6 percent of the men. When asked what the reason for interruption was the majority of patients (52\%) ticked the box “other” and not any of the boxes indicating side-effects as we would have thought, followed by alternative treatment (38 \%). Only 10 percent interrupted their treatment due to side-effects and 20 percent due to commencing treatment for another disease.

The most frequent side effect reported was peripheral neuropathy with 45\% of the men and 48\% of the women. Less interest in sex was more often reported by women, and headaches more reported amongst men. No significant difference regarding side effects between the two sexes was obtained. These common side effects are due to the fact that stavudine is still the first line treatment in Tanzania (e.g. Triomune containing stavudine, lamivudine, nevirapine) which has PNP and fat redistribution as common side-effects. In comparison in the study performed in Ilembula 32\% of the women 36\% of the men had PNP after more than 2 years on ART, and 22\% of the women and 14\% of the men had PNP after more than 1 year on treatment\textsuperscript{8}. This shows a significant increase of PNP with longer duration of treatment. Fat redistribution with more abdominal fat was also significantly more prevalent in our study compared to 6 percent for women and null men in the Ilembula study where patients had been treated for only a year\textsuperscript{8}.

![Graph showing reported side-effects due to ART](image.png)
Other means to treat HIV

The most common other means used to treat HIV besides ART, in percent, was lishe bora (75%), meaning balanced diet. The second most common means that patients use to help is prayer (60%). Almost one third of the patients (31%) used nutritional supplements. Most of these patients (85%) felt the supplementary treatment was helping them. The difference between men and women was not significant, 88 percent of the women felt it was helping them and 82 percent of the men.

Counseling about diet was given at the clinic since nutrition is important in coping with the disease in strengthening the immune system and in combination with ART that can give anorexia, diarrhea, nausea, vomiting and anemia.
Sexual risk behavior

Fig 17. Disclosure of HIV-status before involving in a sexual relationship, in percent.

Thirty-six percent of the women and 39 percent of the men did not disclose that they were HIV positive before getting involved in a sexual relationship. No significant difference was seen between the genders. This might be due to the fact that many of the patients thought that by taking ARVs they were not contagious. According to the patients’ answers about disclosure fig 28 the most common reason was that they were afraid to be discriminated against (61%). Among other common answers were feeling ashamed, fear of being left by their families and the fact that nobody needed to know.

If you have been diagnosed with another sexually transmitted disease, which of the following STDs have you been diagnosed with?  N=38

Fig 18. Reported STDs, in percent.

Of the participants 19 percent (N=38) had been diagnosed with another sexually transmitted disease. The difference between the genders was not significant. Of these patients 31 percent had been infected with syphilis and 21 percent with gonorrhea.

Condom use

Most of the patients claimed they always used a condom in steady sexual relationships (46%) and 13 % answered sometimes, and 13 % did never use a condom. There was a tendency towards more
frequent condom use among men (59%) compared to women (39%). The results are similar to the report from Nkinga in rural Tanzania²⁶ where 53 percent of the men and 33 percent of the women always use condoms. There are more men than women reporting condom use in both studies which may be due to the fact that there is more difficult for women to propose to use a condom, the initiative has to come from the man.

If you have a regular sexpartner and you don't use a condom regularly, why is that?

![Bar chart showing reasons for not using condoms](image)

Fig 19. Different reasons for not using condoms, in percent.

The most common reason not to use a condom was other reasons then the ones being mentioned in our questionnaire, followed by the fact that they were treated with HIV medication. This also correlates with an earlier question X in the questionnaire, where patients believed that they were not contagious when treated with ART. In the interviews many female patients claimed they could not start to use a condom together with their partner, since their partner did not know they were HIV positive. The reason was a lot of fear of being left from their partner. There was a significant difference between men (3%) and women (19%) having partners not wanting to use a condom. A tendency towards more men with HIV positive partners was observed. It is also a very important discovery that 15 percent of the women and 17 percent of the men do not use a condom because they were treated with ART. It is of huge importance to improve the information given to the patients. It has been shown that people having multiple sex-partners use condoms more frequently than those in steadier relationships²⁷.

To compare with people at Muhimbili not having HIV: Only 50 percent of males compared to 43 percent of females had ever used a condom and fewer than 8.3 percent of female youth used other contraceptive methods²⁸.
Economical and social factors related to HIV

Do you have more capacity work when using ART than before?

Most of the patients, 85%, including both sexes, claimed they had a lot more capacity to work since starting ART. This shows significant improvements in health that could have an effect on patients' economical welfare as well.

Have your or your family's economy improved since starting HIV treatment?

The majority of the patients, 61%, reported that their economy had improved since starting with ART.
Most of the patients (64%) have had a negative effect on their economy since becoming HIV positive. This was related to expenses correlating to treatment, (40%), termination from work (14%) and too weak to work because of illness (15%) as shown in the figure below.

There were 42 patients answering that expenses related to treatment was the main reason for decreased economy i.e. 40%. Of these patients, as much as 71% had an income. However, of a total number of 30 unemployed patients, only 14 answered the question. A total of 16 patients answered that they were too weak to work and therefore had a loss of income. Of these 16, eight were still employed or self-employed and six were retired or terminated from work. A total of 17 patients (16%) that answered this question had terminated from work.

TB
Thirty-five percent (N=113) of the women had or had had TB, compared to 30 percent (N=54) of the men. According to WHO, the risk for acquiring TB is 20 to 37 times greater for people infected with HIV. TB is for many Tanzanians seen as a fact that a person is infected with HIV. In some regions in
Sub-Saharan Africa, there are reports measuring that up to 80 percent of patients with TB are infected with HIV. According to WHO, the prevalence of TB in Tanzania among the general population is 0.46 percent\textsuperscript{40}.

**Disclosure**

![Bar chart showing HIV disclosure by relationship and gender](chart.png)

*Fig 23. Disclosure of HIV-status, in percent.*

Only 6 percent of the patients had not told anyone they were HIV positive and only 45 percent had told their partners. It must be taken into count that many were without a partner.
Fig 24. Reasons not to disclose HIV-status, in percent.

The most common reason not to tell other people about their disease was the fear of being discriminated against followed by feeling ashamed of having HIV. No significant difference was seen between the genders.

Compared to a study conducted in Ilembula, where 16 percent of the women and 20 percent of the men were afraid their partners would leave them, our results do indicate a lower frequency. Patients were also asked if they were worried that the HIV medication would make it difficult to hide that they were HIV positive and 26% answered yes (N=167).
Health status

Fig 25. Health status scale, ranged from “1” to “5”, where “1” is a very low health status and “5” is a very high health status, in percent.

The average before starting treatment was 2.8 compared to 4.7 after receiving treatment. There was a significant improved health status after treatment. Studies performed in Ilembula where patients had been on ART for at least two years showed similar results.

Interruption of medication

There was a tendency towards more women 13% (N=114) compared to men 5% (N=51) having interrupted or stopped HIV treatment. The most common reasons were other (44%), which could imply economical or social factors, followed by alternative treatment (29%) and commencing treatment for another disease (18%). Only 9% interrupted their treatment due to side effects. Altogether 34 patients answered this question.
Information collected from patient files
Patient files were obtained for 182 patients. Type of antiretroviral treatment (ART), CD4+ count, adherence assessments, pill count, adverse reactions and Karnofsky score were collected. Duration of treatment to specific antiretroviral drugs was only specified in 176 cases.

The types of antiretroviral drugs that were used to initiate treatment are shown in the figure below.

Fig 26. Type of ART when initiating treatment, in percent.

At the time of our study, there had been a shift in type of ART for many patients from Triomune to Combivir as shown below.

Fig 27. ART among the patients at the time of the study, in percent.

Duration of treatment among the 176 patients was on average 39 months i.e. 3.25 years. (Median 39 months, range 24-69 months). Most patients did change type of drug during this time, seventy patients (39%) never changed treatment regimen.
From the patient files we also noted the reasons for changes of antiretroviral drugs and found that as many as 108 patients of 182, (59%), had changed their medication to another type of ART at least once during their treatment. The reasons for the first change of medication have been noted in 83 cases and are shown in the figure below. This applied to 43% of the women and 37% of the men.

![Reasons for change of ART](image)

Fig 28. Reasons for changing ART regimen, in percent.

As many as forty patients have changed their medication a second time, the reasons not always being clear and six patients changed their medication also a third time. Nine patients were standing on the ART Kaletra, abacavir, didanosine at the time of our study, as a result of insufficient compliance.

**Adverse reactions to treatment**

The most commonly used ARTs were Triomune consisting of the NRTIs stavudine + lamuvudine + the NNRTI nevirapine, as well as Combivir consisting of the NRTIs lamivudine + zidovudine in combination with either the NNRTIs nevirapine or efavirenz.

**Triomune**

Triomune 30 or 40 mg was used by 149 of 176 patients (85%) at some time during their treatment. Eighty-six patients in this group have changed their medication to another type of ART (58%) and 66 of these were caused by side-effects. Another 25 patients had side-effects but continued with Triomune, 37 patients have never had any side-effects. In 77 cases we know the reason for change as shown in the figure below.
Peripheral neuropathy (PNP) appeared already before one year of treatment in 32% of the cases, before two years 61% of the patients had symptoms of PNP and another 39% before four years of treatment. Lipodystrophy appeared after around two-three years of treatment, but never before one year of treatment.

**Combivir and nevirapine**
Sixty patients had at some point during their treatment used Combivir and nevirapine in combination, 25% of these changed this medication during treatment. Change because of side-effect was only noted in one of 60 cases and it might be the effect of earlier treatment with Triomune. Nevirapine has been associated with severe liver injury and serious allergic reactions including the Steven Johnsons syndrome⁷.

**Combivir and efavirenz**
Seventy-six patients used Combivir and efavirenz in combination sometime during their treatment. Only two patients changed medication because of PNP without being treated with another type of ART earlier, and one because of lipodystrophy but had then used Triomune prior to the present regimen. Fifty-two patients (68%) did not have a change of medication. Efavirenz might be teratogenic and is contraindicated in pregnancy⁷.

**Conclusion:** The most common side-effect was peripher polyneuropathy (PNP), 64%, compared to other side-effects. It is a common side-effect caused by stavudine alone or in combination with didanosine. (http://www.aidsetc.org/aidsetc?page=et-03-00-03). PNP has also been the reason for change of treatment regimen in 41% of the cases. The shift has been from Triomune to Combivir over time.
Laboratory data
The following data is based on CD4+ counts recorded for 142 patients. The first and last CD4+ count is analyzed and the mean duration of treatment is shown in the table. For seven patients the sex was not reported.

<table>
<thead>
<tr>
<th>Time on ART until the latest CD4 notation</th>
<th>Median</th>
<th>Mean</th>
<th>Range</th>
<th>2-3 years</th>
<th>3-4 years</th>
<th>4-5 years</th>
<th>5-6 years</th>
<th>&gt;6 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 years</td>
<td>3.3 years</td>
<td>7-78 months</td>
<td>41%</td>
<td>34%</td>
<td>22%</td>
<td>3%</td>
<td>0.7%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CD4+ value at the start of treatment</th>
<th>Median</th>
<th>Mean</th>
<th>Range</th>
<th>Woman mean N=91</th>
<th>Men mean N=44</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>117</td>
<td>141</td>
<td>0-974</td>
<td>148</td>
<td>117</td>
<td>117-165</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CD4+ value latest registered (end of treatment)</th>
<th>Median</th>
<th>Mean</th>
<th>Range</th>
<th>Woman mean N=91</th>
<th>Men mean N=44</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>409</td>
<td>507</td>
<td>15-883</td>
<td>487</td>
<td>456</td>
<td>434-580</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mean difference in CD4+ value between start and end of treatment</th>
<th>Women</th>
<th>Men</th>
<th>Difference</th>
<th>Range woman</th>
<th>95% CI Woman</th>
<th>Range men</th>
<th>95% CI men</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>331</td>
<td>337</td>
<td>6</td>
<td>-639 - 1352</td>
<td>298-364</td>
<td>2-883</td>
<td>147-275</td>
</tr>
</tbody>
</table>

Table 1. Statistical information about CD4+ levels at initiation of ART and at the time of our study.

The CD4+ count correlates strongly to adherence and a drop in CD4+ could imply poor adherence. At every monthly visit, the number of missed tablets during the last month and week is also recorded and thereafter the patients are given a note in their file of having a good or poor adherence. The Karnofsky score was also noted as a measure of the patients’ health status. Treatment failure was indicated when CD4+ count dropped 50% within six months.

We found that as many as 177 patients (94%) were reported to have a good adherence during their last follow-up visit. Karnofsky score were on average 89% when initiating treatment and 97% the last follow-up visit. CD4+ levels had increased with 52% for women and 59% for men, since the start of ART.

Conclusion: The recorded assessment of adherence in patient files correlates well with the adherence level reported from the questionnaire. An increase in the CD4+ level was seen for both men and women as well as the Karnofsky score with an increase of average 8% which also confirms good adherence and treatment success.
General Discussion

A good adherence was observed among our patients despite the fact that one third of them reported that they were experiencing obstacles in order to follow the treatment. The most common obstacles were transportation to and from the clinic and the frequent visits to the clinic. Many patients complained about the opening hours and the long waiting times, since it is very difficult to keep up a good service with such limited resources. \(^\text{16}\)

Many patients claimed during the interviews that the frequent visits to the clinic also made it difficult for them to keep their HIV-status a secret from employers or coworkers. Many patients took their medication at other times than prescribed, when no one else could notice them. \(^\text{16}\) Only 5% of the women and 2% of the men had disclosed their HIV-status to their coworkers. Some patients claimed they were afraid to lose their job, and therefore made excuses to be able to come to the clinic. \(^\text{16}\)

The most common reason not to reveal their HIV-status was because of fear to be discriminated against. However, less than 10 percent reported in the questionnaire that it was due to fear of losing their job. According to a study made in 2006, the human rights of people living with HIV and AIDS were violated in a variety of ways, including termination or refusal of employment, and denial of the right to earn an income, produce food or obtain loans. The informants living with HIV and AIDS were also abused verbally and physically. \(^\text{14}\)

Further improvements could therefore be made regarding the social implications correlating to hospital visits and disclosure. A more accepting attitude in society is needed towards HIV-positive people. Discrimination is a serious obstacle in order to follow treatment as intended by the health professionals and collaboration between the health sector and other sectors of society is necessary to improve both the social situation for the patients and adherence and hence the spread of the disease.

We obtained a very dissatisfying result regarding knowledge about HIV, especially transmission. The fact that less than 50% thought they were no longer contagious when being under treatment is an important observation. There was no correlation to educational level since the patients in our study had a higher educational level than the patients in a study conducted in Ilembula. Still our patients showed a lower knowledge about HIV. This could imply that more resources need to be allocated for HIV education among the patients attending the clinic. Many patients, especially the men, reported that too little information was given regarding the treatment as well.

The poor knowledge about HIV and treatment can also be the reason for the insufficient use of condoms amongst our patients.

The HIV-testing was done very late after infection, and less than fifty percent of our patients had a partner tested for HIV. To promote that tests being taken earlier and to recommend the partners to get tested more frequently are also areas than needs to be improved since the fact that many patients keep their status a secret makes the control of the disease very difficult.

Many social differences between men and women were found in our study. Women were more frequently unemployed and widowed. They had more difficulties disclosing their HIV-status to their partner then the men and the reason was fear of being left. \(^\text{16}\) There are also many orphans and widows deprived of their inheritance rights by relatives of their diseased husband and widows are often blamed for their husband’s death. \(^\text{3}\) These facts are likely to be some of the reasons to why women more seldom disclosed their HIV-status.
Regarding the economical status, almost two thirds of the patients reported that their economy was negatively affected since receiving the HIV-diagnosis and the most common reason was expenses related to treatment, for example loss of income the day they had an appointment with the clinic. The cost for supplementary food and transportation during the visits to the clinic has been shown to be an obstacle for patients on ART in Tanzania in earlier studies as well.

More than two thirds claimed their economy had improved since starting ART which correlated well with the self-assessed health status where the majority reported an increase in capacity to work after starting with ART. On average four people were depending on economical support from the patient. The disease therefore affects the welfare of whole families and not merely the patient’s own. Treatment seems to improve the economical situation in terms of more capacity to work and improved general health. However costs related to treatment is still an obstacle.

To minimize the problems of expenses related to treatment, ART programs could provide for transport and food expenditures, and three months refills instead of monthly refills especially among the stable patients regarding adherence, CD4+ levels and disease development. This would also minimize the lost income due to hospital visits.

Information from the patients’ files showed a good adherence to treatment assessed through pill-count, CD4+ levels and Karnofsky score. Weight gain and reduced morbidity by opportunistic infections and improvements in life quality were associated to treatment success in most cases as well as the increase in CD4+ count. The opposite may indicate treatment failure and consideration of changing regimens.

Treatment success also needs to be put in relation to adverse effects of medication. We found that more than half of the patients had changed treatment regimen at least once during their treatment and that most of them changed because of development of side-effects.

Besides the physical discomfort related to side-effects some of these drugs also leads to stigmatic changes to the body such as lipoatrophy in the face, mainly caused by stavudine. This is very unfortunate since discrimination is a major problem for adherence to treatment amongst the patients and also affects their quality of life negatively.

Another difference between Sweden and Tanzania is that in Sweden ART is initiated earlier, often when the cell count is around 350 cells/ mm³. The difference in eligibility criteria for initiation of treatment is probably due to the use of newer treatment regimens in Sweden, with ART drugs that has lower adverse effects than the older drugs. Postponing the treatment also means postponing adverse effects of treatment, as well as the newer drugs being more secure when it comes to virus resistance and viral loads. The cost of these new medicines is of course a major factor as well.

Conclusions

- Adherence to ART among patients treated for on average three years, showed the same good results as have been seen in other studies performed with patients treated for a shorter duration of time. Adherence did not drop as one could have expected due to treatment fatigue and cumulative adverse effects. However, further studies are required regarding drop-outs from the clinic.
• The main obstacles that patients encounter in order to follow treatment was reported to be logistical problems, too little information about the treatment and discrimination.

• Discrimination is affecting the patients’ adherence.

• The knowledge about HIV was poor especially regarding transmission and is perhaps the finding that most easily can be improved.

• A majority of the patients reported to have a better health status and more capacity to work since starting ART.

• Side-effects were abundant. The most common was peripheral neuropathy, most likely due to the use of stavudine and was also the most common reason for change of treatment regimen.

• The use of condoms was poor. Reasons for this pointed towards the fear of disclosure and thinking they were no longer contagious while medicating.

• Women had a significantly lower social and economical status.

**Limitations**

A great part of the patients were not able to read the questionnaire by themselves due to analphabetism or poor vision. It was therefore necessary to read the questionnaires out loud to these patients. Due to lack of space in the hospital several patients had to be put, in the same room. Some of these times a doctor working in the hospital were working in the same room as the participants. This might have had an effect on the patients’ answers.

The language barrier was another difficulty to overcome. Our questionnaires were translated into Swahili, and some nurses working at the hospital participated in our team as interpreters. Problems occurred during the times the interpreter could not be present, since some of the patients had difficulties understanding the questions. The presence of the interpreter could also have had an effect on the patient’s answers, due to fear of interfering with their doctor-patients relationship.

Many of the patients had not been participating in studies before, and had therefore not seen a questionnaire of this type. Some of the answers received had to be excluded from the study, since some answers were not possible to analyze. Some of the questions had not been filled out correctly by the greater part of the participants, because they were not formed properly. The material received from these questions was therefore excluded.

The greater part of the patients visiting the clinic was women. Due to this fact we have more women participating in our study than men.

Some of the questions were very personal, including sexual behavior, and could therefore have been affecting the answers due to fear regarding anonymity and shame.

The files of the patients were sometimes missing. Very few patients had registrations regarding their viral load and studies comparing viral load with medication was not possible.
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23 Miriam Karlsson, Annelie Markström Sahlgrenska Academy, Rune Andersson, MD, Skaraborg Hospital, Sweden. Charles Lunogelo MD, Godfrey Mpumilwa, Ilembula Lutheran Hospital, Tanzania. High adherence but only 30 percent are still attending the clinic after 2.5 years of antiretroviral treatment.
Appendix 1.

<table>
<thead>
<tr>
<th>KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS</th>
<th>RATING (%)</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to carry on normal activity and to work; no special care needed.</td>
<td>100</td>
<td>Normal no complaints; no evidence of disease.</td>
</tr>
<tr>
<td></td>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td></td>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>Unable to work; able to live at home and care for most personal needs; varying amount of assistance</td>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>Score</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
<td></td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care.</td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent.</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
<td></td>
</tr>
</tbody>
</table>

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.

Source: [http://www.hospicepatients.org/karnofsky.html](http://www.hospicepatients.org/karnofsky.html)