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LIVING ON AIDS TREATMENT: A SOCIO-ECONOMIC PROFILE OF AFRICANS RECEIVING ANTIRETROVIRAL THERAPY IN KHAYELITSHA, CAPE TOWN

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Living on AIDS Treatment: A Socio-Economic Profile of Africans Receiving Antiretroviral Therapy in Khayelitsha, Cape Town

Abstract

This paper analyses the socio-economic impact of providing antiretroviral therapy to AIDS-patients in Khayelitsha, Cape Town. The analysis employs data from a 2002 panel study of AIDS-patients receiving ARV treatment. This sample is placed within a comparative context by reporting comparable data from a 2000/1 survey of Khayelitsha. The comparative analysis shows that ARV patients suffered higher rates of ill health and experienced lower labour force participation rates than the Khayelitsha sample. Findings from the 2002 panel survey indicate that, after one year of treatment, the health status and labour force participation rate improved significantly for ARV patients.

1. Introduction

In May 2001, the Western Cape Provincial Government in collaboration with Medecins Sans Frontieres (MSF) launched a pilot programme to provide highly active antiretroviral (ARV) therapy for AIDS-patients in Khayelitsha. Khayelitsha is Cape Town's largest African township and is home to many unemployed and poor people (Nattrass, 2002). It is thus a test case for exploring the challenges of offering an AIDS treatment programme in a poor urban community and assessing the impact of treatment on the socio-economic status of ARV patients.

In January 2002, researchers from MSF and the University of Cape Town conducted a socio-economic panel study of people who had just started ARV therapy.[1] In the 'base-line' interview, each person was asked questions about who they had disclosed their HIV status to, and about their basic socio-

[1] We would like to acknowledge the following people who were involved in the design and implementation of the surveys used in this paper: The ARV Survey (Marta Darda, Toby Kaspar, Eric Goemere, Emi MacLean); and the Khayelitsha Mitchell's Plain Survey (Murray Leibbrandt, Nicoli Nattrass, Dudley Horner, Jeremy Seekings, Owen Crankshaw, Francis Wilson and Kermit Anderson). Marta Darda and EmiLou MacLean designed the MSF survey and managed the data collection.

economic characteristics such as labour-market status and income. One hundred and thirty seven base-line interviews were collected in 2002.[2] Respondents were re-interviewed on a six-monthly basis in order to explore the socio-economic impact of providing ARVs. The working hypothesis of the study was that restoring an individual's health is likely to reduce the burden of care on the household, reduce health-care expenditure and increase the number of hours the individual could be productively employed or search for work.

This paper paints a socio-economic picture of Khayelitsha residents who started ARV treatment in 2002. In order to locate these respondents within an appropriate broader context, comparative data is presented from a representative sample of Khayelitsha residents who were interviewed as part of the Khayelitsha/Mitchells Plain survey of 2000/1. This enables us to see how the socio-economic situation of people living with AIDS compares to that of the broader population of Khayelitsha residents. The paper also describes the key changes that have taken place over time for those 104 ARV patients who remained in the sample after one year of treatment.

1.1 Selection into the Programme

When the ARV pilot project was designed, selection into the programme was to be determined according to a set of clinical, behavioural and socio-economic criteria (MSF *et al*, 2003). Patients had to meet all the selection criteria in order to be included. As outlined in MSF (2003), these were as follows:

1. Clinical Criteria
   - World Health Organisation classification of being in Stages 3 or 4, or asymptomatic patients with $CD4^+$T cell counts of less than $50/mm^3$.
   - Karnofsky Performance Score greater than 40%

2. Biological Criteria
   - Two tests confirming HIV serostatus (either ELISA or Rapid tests);
   - $CD4^+$T cell counts from 0 to 200/mm;

3. Ability to adhere to therapy
   - Attended the clinic for at least three months;
   - Arrived on time for the previous four visits;
   - Able to take medication regularly.

[2] See Coetzee (2003) for the initial 'base-line' report.

4. Social Criteria

- A fixed address in (greater) Khayelitsha for more than three months;
- Stable home environment and treatment support structure;
- Not on a medical aid scheme which provides ARVs;
- Commitment to attend a support group regularly;
- Open about HIV status and ready to commit to long-term ARV treatment;
- Priority to be given to patients who have dependents or who are very poor.

Criteria 3 and 4 introduced a set of behavioural and social criteria which were likely to result in the sample of ARV patients manifesting a degree of selection bias. In other words, the sample of ARV patients is unlikely to be a random selection of potential ARV patients. This is because the social and behavioural criteria select against richer people, against those who do not wish to disclose their HIV status, and against those judged to be living without an adequate support infrastructure. However, according to those managing the programme, no one who manifests the requisite clinical signs has been denied treatment. This is in part because the disclosure criterion was judged to have been fulfilled if the patient had disclosed to one other person (who was to act as a treatment assistant). It was also in part the result of counselling received from the clinic to help those who initially did not comply (for example not arriving on time for appointments). No person was turned away because they were judged to be too well off.

This suggests that the sample of ARV patients can probably be judged to be a fairly representative sample of people with AIDS presenting themselves to clinics for treatment. Note that this does not mean that the sample of ARV patients can be regarded as a representative sample of people with AIDS in the area. This is because not all people with AIDS present themselves to clinics for treatment. Many may never know their HIV status and die unassisted, while others may choose instead to seek out alternative therapies (e.g. visit traditional healers) instead of visiting the clinic. Pregnancy seems to be one of the key determinants of a person participating in a voluntary counselling and testing programme – which is why treatment programmes are overwhelmingly dominated by young women. Thus, to the extent that the sample of people who know their HIV status is not a random selection of the general population of HIV-positive people, the sample of those on treatment thus manifests a degree of selection bias. However, this is not a function of the selection criteria (as these appear to have had no impact in terms of turning potential patients away), but rather a function of factors exogenous to the programme – most obviously gender.

1.2 Disclosure of HIV Status

Given that disclosure of HIV status was one of the criteria for selection into the ARV programme, it is worth exploring the nature of that disclosure. As can be seen from Table 1, 82.5% reported that they had disclosed to one or more family member, and of the two-thirds of the sample who reported having a (sexual) partner, 85.1% reported having disclosed to him or her. However, it is worrying to note that significantly fewer individuals disclosed to more than one family member than those who disclosed to at least one family member. Only about a third of respondents (35.6%) reported having disclosed to at least one friend and at least one family member. There is thus a significant group of respondents who disclosed to only one person at the start of their ARV treatment. This is a very low level of disclosure – and it is possible that the only reason why they disclosed was to get access to the ARV treatment.

Table 1: Disclosure of HIV Status in the Base-Line Interviews

	Number (total N=137)	*% of valid answers*	*% of sample failing to answer*
Disclosed to their support group	98	72.6%	1.5%
Disclosed to one or more friend	47	34.8%	1.5%
Disclosed to one or more family member	113	82.5%	1.5%
Disclosed to one or more friend and one or more family members	48	35.6%	1.5%
Disclosed to partner only	18	21.7%	1.5%
Disclosed to more than one friend	36	27.7%	2.9%
Disclosed to more than one family member	73	57.9%	8.0%
Disclosed to more than one friend and more than one family member	23	18.7%	10.2%
Disclosed to their partner*	80	85.1%	3.7%
Disclosed to their partner if they also disclosed to more than one friend*	23	100%	4.2%
Disclosed to their partner if they did not disclose to more than one friend*	53	79.1%	1.5%
Disclosed to their partner if they also disclosed to more than one family member*	37	78.7%	6.0%
Disclosed to spiritual leader	22	16.5%	2.9%
Disclosed to current or former employer	13	10.2%	7.3%
Public disclosure	11	8.5%	5.8%

*This only considers the 69% of the sample who reported having a partner.

More respondents reported having disclosed to more than one family member than having disclosed to more than one friend. This suggests that respondents find it easier to be more open about the HIV status to family rather than to friends. Perhaps they believe that family members are more likely to be discreet than their friends. To the extent that family members suffer from reflected stigma (i.e. stigma that arises from living in the same household or being related to someone with AIDS), one might suppose that this assumption about discretion is correct. However, very little is actually known about the nature of the stigma and reflected stigma associated with people living with AIDS in Khayelitsha.

It is interesting to note that of those who disclosed to more than one friend, 100% of those with sexual partners disclosed to their partners. This suggests that once an individual has taken the step of disclosing to more than one friend, that such disclosure is effectively public – and hence it is impossible not to disclose to the sexual partner (as he or she is likely to hear about it 'through the grapevine'. The same pattern does not hold for those disclosing to one or more family member. Put differently, taking the step to disclose to friends is associated with taking a similar step to disclose to a sexual partner – whereas this is not the case with regard to disclosure to family.

As noted above, 137 people were included in the baseline study. Of these, only 104 answered the second questionnaires a year later. Most of the missing respondents died; there was a 16% death rate (MSF, *et al*, 2003: 5). If we compare the levels of disclosure in the ARV sample of those who had been on treatment for a year, then we can see that disclosure levels increased substantially over the period with regard to friends and family members (see Table 2).

The story for disclosure to partners, however, is more complex. As can be seen from Table 2, the answer to the question: "Have you disclosed to your partner?" changed significantly over the period. At the start of the programme, 30% of the sample reported that they had no sexual partner. One year later, only one person reported not having a sexual partner. This is clearly an indicator of restored health – and is consistent with two parallel studies of these same ARV patients; one measuring clinical improvements (MSF, 2003); and the other probing quality of life (Jelsma *et al*, 2003).

According to the clinical study, the proportion of patients with undetectable loads rose to 83% after a year on treatment, and median weight gain was 10.kg per patient (MSF, 2003: 5). These are strong indications of substantially improved health status. The study measuring changes in quality of life (Jelsma *et al*, 2003) found that the ARV patients at base-line (i.e. just as they were about

to start treatment) had significantly poorer quality of life (measured on a range of factors) than was the case for a sample of people from the community. However, after 6 months of treatment, the quality of life of ARV patients was comparable with that of the community sample. In other words, both the clinical and quality of life studies provide ample evidence of improved health for the ARV patients.

Table 2: Changes in Disclosure for the 104 people who Remained Part of the Sample

	At the start of the programme (base line)	*After one year of treatment*
Percentage disclosing to more than one friend	32.0%	56.7%
Percentage disclosing to more than one family member	60.6%	77.9%
Have you disclosed to your partner?		
Yes	53.9%	19.2%
No	11.5%	79.8%
I don't have a partner	29.8%	1%
Missing answer	4.8%	0%
Total	100%	100%
The percentage of those with sexual partners who disclosed to their sexual partners	82.4%	80.4%

It is thus not surprising that more ARV patients had sexual partners a year after being on treatment than at the start of treatment. Disclosure rates (for those with sexual partners) dropped slightly over the year, but not significantly so.

2. Socio-Economic Profile

This section of the paper provides a socio-economic profile of the ARV patients. A comparative context is provided by the Khayelitsha/Mitchell's Plain (KMP) survey which was conducted in 2000/1. This random survey interviewed all adults over the age of eighteen in each household in Khayelitsha and Mitchell's Plain. A sample of 2,644 individuals was obtained in the process. If the sample of adults is restricted to African adults below the age of 59 and over the age of 20 (in order to provide a better point of comparison for the ARV sample, all of whom were Africans and below the age of 56), then a 'restricted' sample of

1,536 African adults is obtained. This paper presents socio-economic statistics for this restricted sample of Africans.

Table 3 summarises basic demographic information in the two studies. It shows that the ARV patients had a far higher proportion of women than was the case for the representative sample of Khayelitsha residents. This is consistent with the higher HIV prevalence rates amongst young women compared to men – hence we would expect the ARV sample to be more weighted towards females than would be the case for the area in general. The average age and school grade attained were, however, comparable between the two studies. The proportion of respondents living with a spouse was almost identical between the two samples, although relatively fewer female ARV patients lived with a resident spouse than was the case for their counterparts in the representative survey of Khayelitsha. Average household size was almost identical between the two surveys. This suggests that ARV patients are fairly typical members of the Khayelitsha community, except for the fact that they are disproportionately women.

Table 3: Key Demographic Characteristics for ARV Patients and a Comparative Sample from Khayelitsha

	ARV patients (base line)	Africans in Khayelitsha
Average Age	33.8	34.4
% women	70.1%	57.5%
% women with a resident spouse	19.8%	28.7%
% with a resident spouse	29.2%	30.9%
% of the total sample with a resident genetic child (or children)	54.0%	56.8%
% women with a resident genetic child (or children)	55.2%	65.8%
% with a genetic child (or children) living in another household*	6.6%	36.7%
% of women with a genetic child (or children) living in another household*	4.2%	36.0%
% of those with no resident genetic children, who have genetic children resident elsewhere*	6.3%	38.0%
% of women with no resident genetic children, but who have genetic children resident elsewhere*	4.7%	40.7%
% of those with resident genetic children who also have genetic children resident elsewhere*	6.8%	55.2%
% of women with resident genetic children who also have genetic children resident elsewhere*	3.8%	61.3%
Highest school grade passed	9.2	8.5
Average household size	4.9	4.6

* The data are not comparable between the two surveys because the ARV survey merely asked if a genetic child had "left" the household – rather than asking if there were any genetic children living in other households (as was the case in the KMP survey).

Significantly more women than men in the KMP samples had resident children compared to the ARV patients. This is perhaps because men who are on antiretroviral treatment are more likely to be living with their children than men in general. This may reflect the fact that men are more likely to seek treatment when they are in a stable family situation than when they are not. It may also, however, reflect the influence of the programme's selection criteria. As noted earlier, the ARV programme requires that patients live in a 'stable home environment' – thus perhaps creating an incentive for HIV-positive men to move back in with their families in order to access treatment.

A higher proportion of women in the representative Khayelitsha sample were likely to be living with at least one of their children than was the case for the ARV patients. This could reflect the fact that people living with AIDS have lower fertility rates than other women. One could also hypothesise that women living with AIDS are more likely to send their children to live in other households because they find the burden of child-care too hard. For example, Oni *et al* (2002) found that some AIDS-affected households in Limpopo sent children away from the household as a coping strategy. But according to the comparative data presented in Table 3, very few of the ARV patients indicated that a child (or children) had left the household. The table also suggests that a far higher proportion of the representative Khayelitsha sample (both for women and for the entire sample) had genetic children living in other households than was the case for the ARV patients. However, the questions asked in the two surveys are not actually comparable. Whereas the Khayelitsha survey asked if there were any genetic children living elsewhere, the ARV survey asked if a genetic child had 'left' the existing household. One would thus expect the Khayelitsha survey to reflect a higher proportion of children living elsewhere.

2.1 Unemployment and Labour-Force Participation

Table 4 explores the labour market status of the ARV patients and places them in a comparative context by using data from the Khayelitsha survey for Africans below 59 and over 20 years of age. The table indicates that the unemployment rates are fairly close between the two surveys. The searching unemployed expressed as a percentage of the labour force (defined as the employed plus the searching unemployed)[3] is the calculation for the *strict unemployment rate*. As can be seen from the table, the ARV patients had a higher strict unemployment rate than was the case for the Khayelitsha sample. However, the case is reversed

[3] The Khayelitsha/Mitchells Plain survey allowed for a fine-tuned exploration of different definitions of unemployment (Nattrass, 2002). The unemployment rates used in this paper follow the definitions used in the ARV survey (i.e. the definition used in the ARV survey was applied to the Khayelitsha sample for the purposes of this analysis).

with regard to the broad unemployment rate. The *broad unemployment rate* includes in the labour force as unemployed those individuals who say they would like a job, but who are not actively searching for work.

Table 4: Comparative Labour-Market Information

	ARV patients (base line)	*Africans living in Khayelitsha*
1. Wage employed	30 (56.6%)	534 (72.1%)
2. Casual employed	6 (11.3%)	50 (6.7%)
3. Self employed	17 (32.1%)	157 (21.2%)
4. *Total Employed* (1+2+3)	*53 (100%)*	*741 (100%)*
5. Unemployed (strict)	34	367
6. Unemployed (broad)	44	695
7. Non labour force participants (strict)	50	397
8. N	137	1505
9. Missing values	0	31
10. Total N (8+9)	137	1536
Unemployment rate (strict) (5/(4+5))	39.1%	33.1%
Unemployment rate (broad) (6/(4+6))	45.4%	48.4%
Labour force participation rate (strict) (4+5)/8	63.5%	73.6%
Labour force participation rate (broad) (4+6)/8	70.8%	95.4%

Researchers who prefer using the strict definition (which is the international standard) do so on the grounds that only active job-seekers should be counted as unemployed, because they (unlike the non-active job seekers) are actually 'participating' in the labour-market. Those who merely report that they would like a job (but are not looking for one) may, according to this view, not really be willing and available for work. Researchers who favour the broad definition, argue that non-active work-seekers are often discouraged (by the lack of jobs) and are too poor to seek work actively (Kingdon and Knight, 2001). In this view, excluding those not actively seeking work from the labour force is simply defining away a real social problem.

The big difference between the ARV patients and the representative Khayelitsha sample is – as is to be expected – with regard to labour force participation rates. The *labour force participation rate* is the number of people who are in the labour force (i.e. are either defined as employed or unemployed) expressed as a percentage of the number of people of working age. The table shows that the (broad) labour force participation rate for the ARV patients was only 70.8% as

opposed to 95.4% for the comparative sample of Africans in Khayelitsha. The high non-labour force participation rate of course reflects the fact that the ARV patients were very ill at the time of the base-line study – i.e. they had reached the clinical stage where they were deemed ready to start ARV treatment. Many of them thus may ideally want to work, but were at the time simply too ill to work or look for work. Of the 40 (broadly defined) non labour force participants, 90% said that they were too ill to work.

Table 5 shows that labour-force participation changed significantly for the ARV patients over the first year of treatment. This is clearly a further sign of restored health as a result of ARV treatment. As shown in Table 5, labour-force participation increased – manifesting itself in an increase in the number of employed and in the number of searching unemployed. Because more people started searching for jobs than were able to find them, the unemployment rate actually rose over the period.

Table 5: Changes in Labour Force Participation for the 104 ARV Patients for whom we have a Year's Worth of Data.

	At the start of the programme (base line)	*After one year of treatment*
Employed	44 (42.3%)	55 (52.9%)
Searching Unemployed	25 (24.1%)	33 (31.7%)
Non-labour force Participants	35 (33.7%)	16 (15.4%)
Total	*104 (100%)*	*104 (100%)*
	Pearson's Chi2= 9.4041 (pr=.009)	
Unemployment rate (strict)	36.2%	37.5%
Labour force participation rate (strict)	66.4%	84.6%
Employment rate	42.3%	52.9%

One way of exploring the link between illness and low labour-force participation is to compare how the ARV patients and the representative sample of Khayelitsha residents responded to a question asking how often health problems interfered with their ability to work or look for a job. As can be seen from Table 6, over half of the ARV patients reported in the base-line survey that health problems were affecting their ability to work at least some of the time. By contrast, only a third of the Khayelitsha sample reported that health problems were affecting them in this way.

Table 6: Health Problems and Labour-Force Participation

How often health problems affected ability to work and look for work	*ARV patients (base line)*	*Africans in Khayelitsha*
All the time	11.2%	1.2%
Most of the time	20.2%	6.1%
Some of the time	20.1%	26.4%
None of the time	48.5%	66.3%

Table 7 provides information on changes over time in reported health status for the 104 ARV patients for whom we have information at base line and after one year of treatment. As can be seen, there were sharp levels of improvement: whereas only 51% of the sample reported in the base-line survey that health problems affected their ability to work or look for work 'none of the time', this percentage rose to 82.7% after a year. The numbers reporting no sick days likewise increased significantly from 60.6% to 90.4%.

In the base line study, 45 percent of ARV patients reported that at least one member of the household took time to care for them. This does not appear to have had much impact on household income, because only seven respondents reported that the caregiver had forgone income-earning opportunities as a result. Only three people reported that a school pupil had missed school to look after them (one reported that one school day had been lost and two reported that two school days had been lost). In other words, unemployed people rather than school children and the employed were picking up the burden of caring for people suffering from AIDS-related illness.

Table 7: Health Problems for the 104 ARV patients who remained in the sample after 1 year of treatment

	Start of the programme (base line)	*After one year of treatment*
How often health problems affected ability to work and look for work		
All the time	9.8%	0.0%
Most of the time	17.7%	0.0%
Some of the time	21.5%	17.3%
None of the time	51.0%	82.7%
Percentage reporting no days in which they were too sick to do their normal daily activities	60.6%	90.4%

2.2 Reasons for Loss of Previous Job

Of the 84 people who were not employed at the time the base line study was conducted, 80% (67 people) reported that they had worked before. Table 8 reports the reasons why these respondents lost the job. Over half (55.3%) lost their jobs either as a result of illness or missing too many days of work. Both of these reasons are likely to be HIV-related. Interestingly, no one reported losing their job because their employer found out about their HIV-status. The second largest reported reason for losing the previous job was retrenchment (29.9%). This is in line with data from the Khayelitsha sample indicating that 36.9% of those who were no longer employed, lost their previous jobs because they were retrenched. Data such as this reflects the very difficult labour market situation existing for people in Khayelitsha.

Table 8. Reasons Given by ARV Patients for Losing Previous Job (Base Line Study)

	Casual	*Full-time*	*Part-time*	*Self-employed*	*Total*	*Total (%)*
I lost my job due to illness	6	16	7	2	31+1*	47.8%
I missed too many days of work	0	3	2	0	5	7.5%
I lost my job due to retrenchment/the company closed	0	17	3	0	20	29.9%
The job was temporary	0	1	3	0	4	6.0%
Other (non-HIV related)	0	3	2	1	6	9.0%
Total	6	40	17	3	67	100%

*1 was a missing value; the person did not answer the question of what type of job was lost.

2.3 Employment

As reported in Table 4, fifty-three respondents in the base line study were classified as being employed. Although most were in wage-employment, a smaller proportion of employed ARV patients were engaged in wage-employment than was the case for the Khayelitsha sample. Proportionately more of the ARV patients were engaged in self-employment and casual employment (although the cell sizes are too small for comfort).

Of the 53 employed, only 44 gave valid responses for income. As can be seen in Table 9, mean income for the wage-employed was R1400 per month (28 out of a possible 30 responses), for the self-employed: R728 per month (11/17 responses) and for the casual employed: R706 (5/6 responses). Average wage income is higher in the Khayelitsha sample (whether adjusted for inflation or

not) than for the ARV patients. This could be because the average age of wage-employed people for the ARV patients was 28, as opposed to 37 in the Khayelitsha sample.[4]

Table 9. Mean Income from Employment

	ARV patients	*Africans in Khayelitsha (2002 prices*)*	*Africans in Khayelitsha (2000 prices)*
Wage employed [range]	R1,400 [R100-R6,000] n=28/30	R1,729	R1,583 [R35-R9830] n=498/534
Casual employed [range]	R706 [R200-R1,400] n=5/6	R625	R572 [R50-R20,000] n=41/50
Self employed [range]	R801 [R190-R3,700] n=10/17	R455	R497 [R15-R3,920] n=61/157
Total [range]	R1,180 [R100-R6,000] n=42/53		RR,375 n=657 [R7-R9,830]

* Adjusted by the consumer price index which rose by 9.2% in 2002 (SARB Quarterly Bulletin, December 2003).

2.4 Household Income

The study of ARV patients asked respondents in each survey whether household income had changed over the past six months. Fifty-seven percent of respondents said in the base line study that it had stayed the same, and 35% reported that it had decreased (only 3% reported it had increased, and 5% said they did not know).

Table 10 provides information on reported changes over time in this variable for the 104 respondents who remained in the sample after a year of treatment. As can be seen, from the table, there was a significant difference between the way the question was answered at base-line, and after a year of treatment. Significantly more respondents reported that their household incomes had

[4] However, the fact that the average school attainment of those ARV patients who were wage-employed was Grade 10, as opposed to Grade 9 in the Khayelitsha sample would have acted as a counterweight to the age premium in the Khayelitsha sample. Unfortunately the sample size for wage employed in the study of ARV patients is too small (n=28) to conduct meaningful earnings function analysis. An earnings function estimated with three explanatory variables (gender, age and education) revealed that the signs were all in the expected direction (being male increased earnings, extra years of education increased earnings and extra years of age increased earnings) but none of the variables were significant.

increased, and significantly fewer reported that their household incomes had decreased.

Table 10. Reported change in monthly household Income for the 104 respondents who remained in the sample after one year of treatment

Has your monthly household income changed in the last six months?	*Start of treatment*	*After one year of treatment*
I don't know	6%	8.7%
Yes, it has decreased	32%	22.1%
Yes, it has increased	3%	19.2%
No, it has stayed the same	59%	50.0%
Total	100%	100%
Pearson Chi2 = 15.0068 Pr= 0.002		

Of those respondents in the base line study who reported having lost their jobs in the previous year, 68% reported that their household incomes had decreased in the past six months. This illustrates the importance of wage income to household income.

Table 11 provides information on the sources of monthly household income for both samples. Household income was calculated the same way in both data sets: income from employment was added to income from grants and income from other sources for all members of the household.[5] However, it is worth noting three important methodological differences between the two surveys which affects comparability. Firstly, in the Khayelitsha survey, each adult was interviewed – and their income data was added together to get a total income estimate for the household. In the study of ARV patients, only one person was interviewed (the clinic attendee) and that person reported on the income for other household members. Secondly, the survey of ARV patients only asked for two categories of income of other household members: income from work, and income from grants (thus, we cannot differentiate between different types of employment income at the household level). Thirdly, the study of ARV patients did not ask about remittances to the household other than to the individual respondent. This is why 'other' income is such a relatively low proportion of total household income for the ARV patients compared to the Khayelitsha sample.

[5] The Khayelitsha Mitchells Plain survey asked more detailed questions about income and hence a more sophisticated estimate of household income can be obtained from this survey (see Skordis and Welch, 2004). Such a methodology was not used here because it would have limited the comparability between the two studies.

Table 11: Composition of Household Income

Percentage of Household Income Contributed by:	*ARV patients (base line)*	Africans in Khayelitsha
Wage income	38.0%	*50.3%*
Income from casual employment		*9.1%*
Income from self-employment		*5.9%*
Grant income	60.8%	*9.4%*
Other income*	1.2%	*25.3%*
Total	*100%*	*100%*

* These figures are not comparable because the ARV survey only asked the respondent about other income – other household members were only asked about employment income and grant income. The Khayelitsha/Mitchell's Plain survey asked all household members about all forms of income.

This almost certainly resulted in a downward bias to household income in the study of ARV patients. If the 'other' income of other household members is excluded from the household income calculation for the Khayelitsha sample, then mean household monthly income drops from R1,606 to R1,518. Taking these estimates as a guide, this suggests that monthly household income for ARV patients is probably underestimated by 5% as a result of the survey asking only about the employment and grant income of other household members.

Table 12: Comparative Income Data (Khayelitsha and the Base Line ARV Survey)

	ARV Patients (2002 prices)	*Africans in Khayelitsha (2002 prices*)*	*Africans in Khayelitsha (2000/1 prices*)*
Household income (mean)	R1,463	R1,754	R1,606
Household income minus disability grant income (mean)	R999	R1,728	R1,582
Average % contribution of disability grant income to household income	31.7%	1.5%	1.5%
Average *per capita* household income	R340	R458	R419
Average household income for those households with a disability income	R1,510	R1,497	R1,371

Adjusted by the consumer price index which rose by 9.2% in 2002 (SARB Quarterly Bulletin, December 2003).

Table 12 presents information on household income. It shows figures for the base line study of ARV patients in 2002 and for the Khayelitsha sample inflated upwards by 9.2% to adjust for consumer inflation between 2001 and 2002. The adjusted figures must be treated with some caution because they assume that all incomes rose in line with consumer inflation – which was probably not the case for many people. However, in order to make the data as comparable as possible with the data from the study of ARV patients, this adjustment was necessary because the two data sets were collected over a year apart.

Two results stand out from Table 12. Firstly, household income and *per capita* household income are similar between the ARV patients and the comparative Khayelitsha sample (adjusted to 2002 prices); although the latter data is consistently higher than the former. Given that the household income of ARV patients is under-estimated by the failure of the survey to capture remittance income going to other household members, we can probably safely assume that average household income levels are for all intents and purposes the same between the two surveys. However, the distribution of household income is much more unequal in the Khayelitsha survey. This can be seen in Figure 1 which plots average household income by income quintile for both samples.

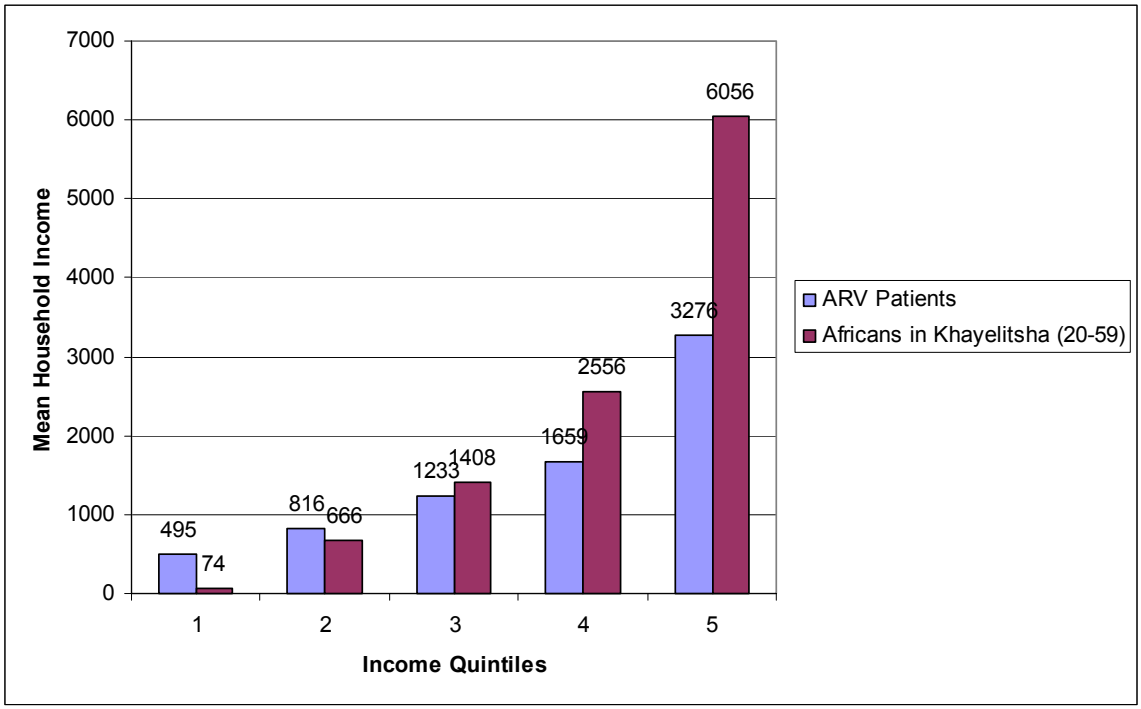

Figure 1. Income Distribution in the ARV and Khayelitsha Samples

The second striking feature of Table 12 is that the disability grant contributes far more towards household income for the ARV patients than is the case for the Khayelitsha sample. This is to be expected because the ARV sample comprises

people with a serious illness – and because the MSF clinic helps ensure that most of the people they have on treatment also access the disability grant. Thus, not only are more people likely to be eligible for the disability grant in the ARV sample compared to Khayelitsha, but they are also more likely to succeed in obtaining the grant if eligible.

The disability grant is subject to various conditions – including a means test and a medical report confirming the disability. Being unemployed is not a sufficient condition for obtaining a disability grant – the individual has to be too sick to work. Seventy-three percent of the sample of ARV patients reported receiving a disability grant. However, of these individuals, 22% reported that they were working. Fifteen percent were classified as wage-earners (earning a mean monthly wage of R1,099), 2% were casual workers and 5% were self-employed. Ten percent of those receiving the disability grant were earning more than the value of the disability grant.

Table 12 also indicates that the average standard of living is low in both samples. An average household monthly *per capita* income of R340 (the ARV sample) is the equivalent of $1.6 per person per day (assuming an exchange rate of R7:$1). Unsurprisingly, then, the largest expenditure item for the ARV sample is food (accounting for an average of 44.8% of total household expenditure). This is followed by 12.7% on transport, 11.0% on savings, 10.1% on education, 9.1% on services (electricity and water) and 5.7% on health.

The share of health expenditure may seem surprisingly low at first glance given that the households in the ARV sample comprise people starting their treatment programme. They are thus in advanced stages of AIDS and hence are likely to be suffering from opportunistic infections. However, as most of their health needs are being met by the Khayelitsha clinic, this almost certainly accounts for the low expenditure share. HIV-related costs are probably being incurred in other ways, e.g. through higher transport costs (if the person is too sick to walk to the clinic). Unfortunately the Khayelitsha survey did not ask questions about expenditure, so it is not possible to contextualise these expenditure patterns with reference to the broader population.

3. Conclusion

This paper attempted to place the sample of ARV patients in a comparative context using data from the Khayelitsha Mitchell's Plain survey. Although differences in questionnaire design limits comparability in a number of cases, there are a few robust findings. The strongest findings are (as one would

expect) that at base-line, the ARV patients suffered from a higher degree of reported ill-health and disability than did the Khayelitsha sample, and that labour-force participation rates were correspondingly lower for ARV patients. Preliminary analysis of the panel data for the 104 ARV patients who remained in the sample, reveals that reported disability and ill-health declined sharply after a year on treatment.

This is consistent with parallel studies using the same group of respondents showing that clinical indicators and quality of life improved significantly during the first year of treatment (MSF *et al* 2003; Jelsma *et al*, 2003). Findings such as these suggest strongly that the increase in labour-force participation and in health status over the period can be attributed in large part to the impact of ARV treatment.

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