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The Impact of Highly Active Antiretroviral Therapy (HAART) on Perceived Health and Labour Supply in Khayelitsha

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Abstract

Many people living with HIV/AIDS have experienced significant improvements in their health as a result of Highly Active Antiretroviral Treatment (HAART). South Africa's public sector rollout of HAART has made treatment accessible to a greater number of people living with HIV/AIDS. The research hypothesis of this study was that over time patients on HAART would perceive that their health had improved, and that their perceptions would influence their labour supply decisions. Cox-Proportional Hazard Models were estimated using panel data collected from 261 HAART patients living in Khayelitsha, South Africa. The analysis found that HAART has indeed resulted in patients perceiving that their health had improved. Deciding whether or not to re (enter) the labour market is, however, a complex decision for a HIV-positive individual, and dependent on specific characteristics that they possess. Perceived health is but one of many factors that inform labour supply decisions. Perceptions of improved health is significant in explaining transitions from being a non-labour force participant to being unemployed. When controlling for all other individual characteristics, perceptions of improved health is not significant in explaining transitions to employment. Patients who have worked before, who live in households with fewer young children to care for, who have not publicly disclosed their HIV status, and who were younger when they were diagnosed HIV-positive, have a greater 'risk' of making the transition to employment.

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Plagiarism Declaration

1. I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.

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Each contribution to, and quotation in, this dissertation from the work(s) of other people has been attributed, and has been cited and referenced.

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Acknowledgements

"If we knew what it was we were doing, it would not be called research, would it?"

Albert Einstein

Research can be a solitary and frustrating exercise, but God has blessed me with the most amazing network of support anyone could wish for.

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Introduction

In the early 1330's the bubonic plague, or The Black Death, wiped out almost one-third of Europe's population¹ (Barnett and Whiteside, 2002). The most striking aspect of The Black Death was how swiftly the infected died. The Italian writer Giovanni Boccaccio, in his book the *Decameron* (1921) said that victims of the bubonic plague often "ate lunch with their friends and dinner with their ancestors in paradise". In the middle ages nothing was known about the causes of, or cure for, the bubonic plague. It was an incurable disease which people fled from in panic. Several centuries later, mankind has once again been inflicted by an incurable disease, HIV – but this time the progression of the disease is slow (with HIV positive people remaining asymptomatic for many years) and treatment is available to manage the disease as a long-term, chronic condition – thereby extending the productive lives of infected people substantially. Highly Active Antiretroviral Therapy (HAART) dramatically improves the health of people living with AIDS. Doctors talk of a 'Lazarus effect'² whereby people at death's door regain their health soon after beginning treatment. Thus, instead of having dinner with their ancestors in paradise, they live to have many more meals with family and friends.

There was an estimated 39.4 million people living with HIV/AIDS at the end of 2004, mostly in Sub-Saharan Africa and China, yet very few were on HAART. According to the World

¹ See www.themiddleages.net/plague 2005 for a more detailed description of the plague

² The Lazarus syndrome is named after a biblical character. In the bible (John 11:38-43) Jesus brought Lazarus back from the dead after he had been in his tomb for 4 days.

Health Organisation, only 12 percent of the global number of AIDS sick people were receiving HAART as of the end of 2004 (WHO, 2004:7). In developing countries the provision of HAART to all individuals who need it has not kept pace with the scale and pace of the epidemics in these regions. In Sub-Saharan Africa only 310,000 HIV-positive individuals aged 15-49 receive HAART, even though it is estimated that 4,000,000 individuals in this region need treatment. In South Africa, one of the worst affected developing countries, it is estimated that between 37,000 and 62,000 of a total estimated 837,000 adults who need treatment, have access to HAART (WHO, 2004).

In South Africa estimated HIV prevalence among individuals in their early 20's and 30's has risen sharply, since 1990 (Figure 1). The pool of productive labour is thus comprised of individuals who have a high-risk of contracting and dying from HIV/AIDS, and during their prime productive years workers face the possibility of debilitating illness constraining their capacity to supply labour (Buve *et al*, 2002, see also Evian, 1991). HAART has the potential to ameliorate this impact substantially.

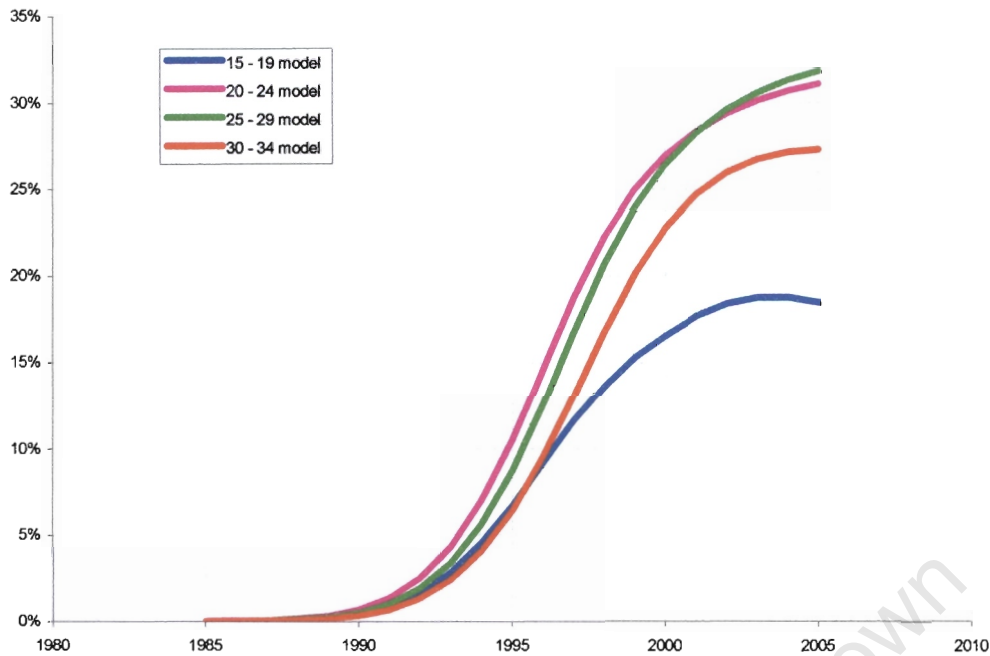


Figure 1: *HIV prevalence in South Africa (1985-2005), by age. (Source: Projections made from the ASSA 2002 AIDS demographic model)*

This dissertation provides a narrative on the link between renewed health - as a result of HAART - and a renewed opportunity for labour supply, and places it within a South African context. More specifically it analyses how HAART affects the health of a sample of men and women living with HIV in Khayelitsha, and how changes in the health of these individuals affects their choice of labour market state (i.e. employed, unemployed or non-labour force participant). To date there is no study that uses longitudinal data to analyse the impact that HAART has on the labour supply of HIV-positive individuals in developing countries. This study takes a step toward filling this gap in the research literature.

The manuscript is arranged in the following manner. Chapter 1 looks at HIV/AIDS and treatment in general, discusses the AIDS pandemic and HAART rollout in South Africa, and introduces the research hypothesis and motivation for this study. Chapter 2 analyses the

impact that HAART has had on perceptions of health within a sample of HIV-positive individuals living in Khayelitsha and receiving HAART. Chapter 3 analyses the impact of HAART on the labour supply decisions of these same individuals.

HIV/AIDS and treatment

The Human Immunodeficiency Virus (HIV) belongs to a family of viruses called retroviruses. HIV's genetic material is in the form of Ribonucleic Acid (RNA). The HIV-virus infects a host cell in a person's body and then copies its own genetic code into the cell's Deoxyribonucleic Acid (DNA). The host, in the case of HIV, is a type of white cell called T lymphocytes, which contains the protein CD4 on its surface. The HI virus uses CD4 to enter the cells it infects. For this reason the T helper cell is referred to as a CD4 lymphocyte. The T helper cell is a crucial cell in the immune system; it co-ordinates all other immune cells so any damage or loss of the T helper cell seriously affects the immune system. Once the HI virus has introduced its genetic material into the cytoplasm of the host cell, the cell is 'programmed' to create new copies of HIV, which it uses to infect new cells (Barnett and Whiteside, 2002; Greene and Perterlin, 2003)³.

³ For a user friendly discussion of the biology of HIV see: www.openchemist.net, accessed 20 March 2005

Table 1: *WHO disease staging system for HIV Infection and Disease in Adults and Adolescents*

Clinical Stage I:

- Asymptomatic
- Generalized lymphadenopathy

Performance scale 1: asymptomatic, normal activity

Clinical Stage II:

- Weight loss <10% of body weight
- Minor mucocutaneous manifestations (seborrheic dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, angular cheilitis)
- Herpes zoster within the last five years
- Recurrent upper respiratory tract infections (i.e. bacterial sinusitis)

And/or performance scale 2: symptomatic, normal activity

Clinical Stage III:

- Weight loss >10% of body weight
- Unexplained chronic diarrhoea, >1 month
- Unexplained prolonged fever (intermittent or constant), >1 month
- Oral candidiasis (thrush)
- Oral hairy leucoplakia
- Pulmonary tuberculosis
- Severe bacterial infections (i.e. pneumonia, pyomyositis)

And/or performance scale 3: bedridden <50% of the day during last month

Clinical Stage IV:

- HIV wasting syndrome [i]
- Pneumocystic carinii pneumonia
- Toxoplasmosis of the brain
- Cryptosporidiosis with diarrhoea >1 month
- Cryptococcosis, extrapulmonary
- Cytomegalovirus disease of an organ other than liver, spleen or lymph node (e.g. retinitis)
- Herpes simplex virus infection, mucocutaneous (>1 month) or visceral
- Progressive multifocal leucoencephalopathy
- Any disseminated endemic mycosis
- Candidiasis of esophagus, trachea, bronchi
- Atypical mycobacteriosis, disseminated or pulmonary
- Non-typhoid Salmonella septicemia
- Extrapulmonary tuberculosis
- Lymphoma
- Kaposi's sarcoma
- HIV encephalopathy [ii]

And/or performance scale 4: bedridden >50% of the day during last month

During World Health Organisation (WHO) clinical stages 1 and 2 the individual will be clinically asymptomatic (Table 1). With the destruction of the immune system cells the body becomes increasingly unable to resist other infections; on average it can be ten years before the individual reaches WHO stage 3, which is the clinically symptomatic stage. As the body's defence system weakens, symptoms appear, alone or in multitude. They include: chronic

fatigue or weakness, diarrhoea, minor skin infections, respiratory problems, sustained weight loss, persistent swelling of the lymph nodes and deterioration of the central nervous system. As the immune system weakens further, more severe AIDS defining opportunistic infections manifest themselves (WHO stage 4), such as cryptococcal meningitis, extra-pulmonary tuberculosis (ETB), pneumocystic pneumonia and cancers such as Kaposi's sarcoma and lymphoma. This more severe phase can continue for about two years before death, with progressively longer periods of illness that may be interspersed with periods of remission. The median time from infection to development of AIDS in industrialised countries is 10-11 years, while in sub-Saharan Africa it is estimated to be 5-10 years (Loewenson and Whiteside, 1997).

There is currently no cure for HIV/AIDS, but medication has been developed that delays disease progression in the later stages of HIV disease. These drugs are known as antiretrovirals because they are used in the treatment of the retrovirus HIV. There are three groups of antiretrovirals that are approved in the treatment of HIV. The first group is Nucleoside Reverse Transcriptase Inhibitors (NRTIs). HIV needs an enzyme called reverse transcriptase in order to infect healthy cells and reproduce itself in an individual's body. NRTIs cause termination of the growing HIV DNA chain, rendering it ineffective, by adding a 'dysfunctional' building block.

The second group of antiretroviral drugs are Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs). This group of drugs stops HIV from infecting cells by intervening with the transcriptase of the virus. The non-nucleoside drugs work slightly differently from the nucleoside drugs in that they bind in a different way to the cell's reverse transcriptase. The non-nucleoside drugs block the duplication and the spread of the HIV.

The third type of antiretrovirals is the Protease Inhibitor (PI) group. Protease inhibitors, as the name says, inhibit protease. Almost every living cell contains protease. Protease is a digestive enzyme that breaks down protein and is one of the many enzymes that HIV uses to reproduce itself. The protease in HIV attacks the long healthy chains of enzymes and proteins in the cells and cuts them into smaller pieces. These infected smaller pieces of proteins and enzymes continue to infect new cells. The protease inhibitors take effect before the protease in HIV has the chance to break down the protein and enzymes. This way the protease inhibitors slow down the duplication of the virus and prevent the infection of new cells. The NRTIs and NNRTIs only have an effect on newly infected cells. Protease inhibitors are able to slow the process of immature non-infectious virus becoming mature and infectious. Protease inhibitors also work in cells that have been infected for a long time, by slowing down the reproduction of the virus⁴.

Highly Active Antiretroviral Therapy (HAART) consists of triple drug therapy, which is a combination of drugs from each of the three groups of antiretrovirals. According to the National Antiretroviral Treatment Guidelines HAART should be initiated in patients with CD4 counts below 200 cells/mm³ irrespective of WHO stage, or when the patient has been diagnosed with a WHO stage 4 disease irrespective of CD4 count (Department of Health, 2004a). The primary goal of HAART is to reduce HIV-related morbidity and mortality. HAART slows the replication of HIV and viral load will decrease as the immune system recovers and the number of T lymphocytes increases (Department of Health, 2004a). HAART cannot reverse the infection of cells that have already been infected but it prevents new white cells from being infected. Thus, HAART does not cure HIV/AIDS but it does slow the patient's progression from HIV to AIDS. It enables people to live longer more productive lives, thereby substantially alleviating the negative effect of HIV on individuals, families and

⁴ For a user friendly discussion of antiretroviral treatment see: www.avert.org

society. If taken properly HAART can extend life substantially. There are people in the United States of America (U.S.A) who have been on HAART for almost a decade⁵. Whether this success can be replicated in a developing country context remains to be seen.

Antiretroviral treatment in South Africa

In just over a decade South Africa has experienced an explosive HIV/AIDS epidemic. The National HIV and Syphilis antenatal sero-prevalence survey states that HIV prevalence among women attending antenatal clinics increased from less than 3 percent in 1990 to 29.5 percent in 2004 (Department of Health, 2004b). South Africa is officially recognised as one of the countries that has the highest national total of people with HIV/AIDS in the world.

In high-income countries the advent and accessibility of HAART has transformed HIV/AIDS into a treatable chronic disease. Prior to the development of generic drugs, developing countries such as South Africa could not afford to rollout expensive antiretroviral treatment to all who needed it. Five years ago antiretrovirals cost US\$10,000 for one patient per year, but now HAART can be bought from generic drug companies such as Cipla in Mumbai, India, for less than US\$ 250 (Kumarasamy, 2004).

⁵ Information available at: www.avert.org

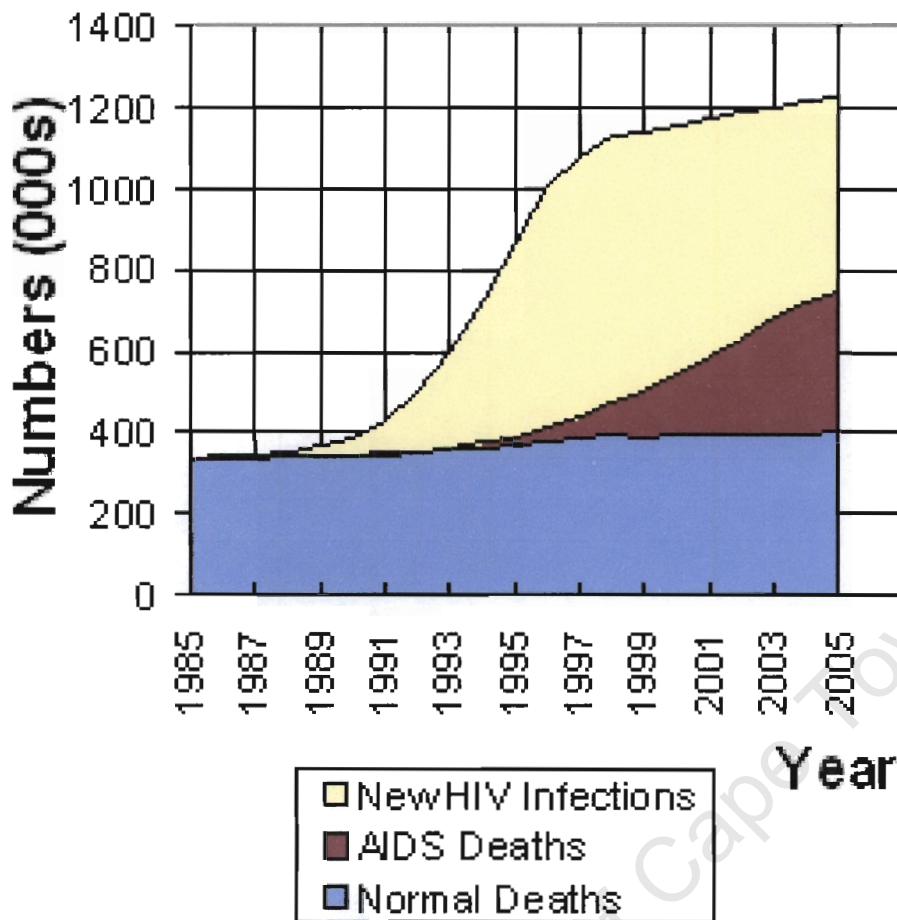
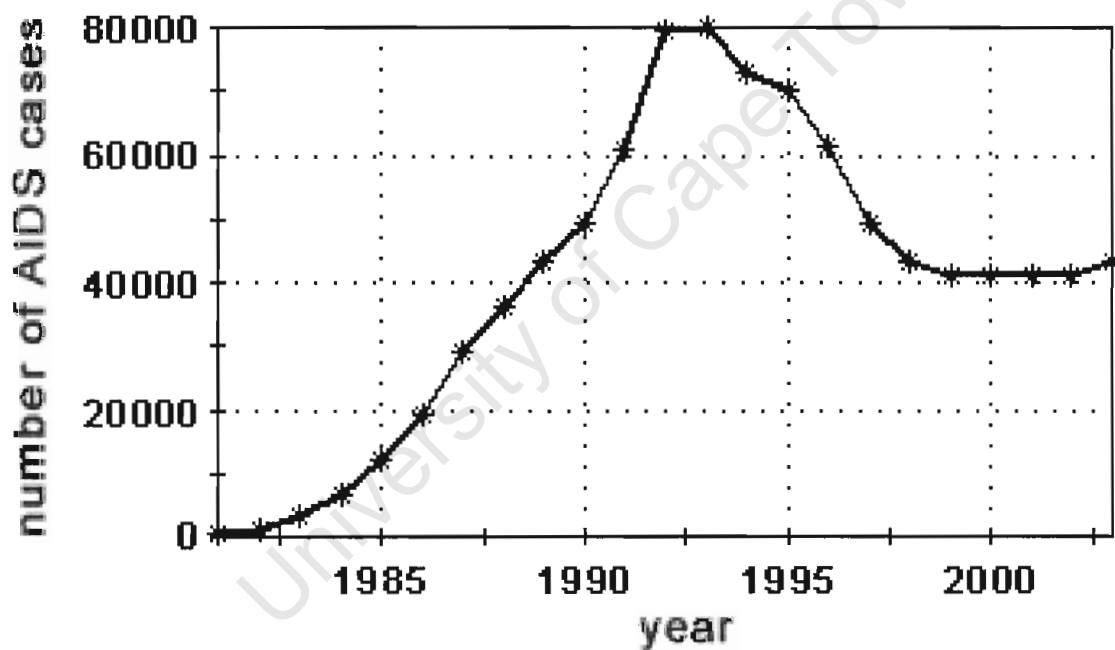


Figure 2: Deaths in the total South African population (1985-2005). (Source: Projections of from the ASSA 2002 AIDS demographic model)

The experience of the U.S.A is an interesting point of comparison for South Africa. While AIDS mortality was increasing in South Africa (Figure 2), the U.S.A enjoyed a reduction in their number of AIDS cases as a result of many of those in need of treatment having greater access to HAART. As shown in Figure 3, after the introduction of antiretroviral therapy in the U.S.A from 1995-1996, AIDS-related deaths fell steeply⁶. Since the late 1990s AIDS deaths have continued to decline in the U.S.A but at a more gradual rate. The rising number of AIDS cases among African Americans most likely explains the gradual rate of decline in

⁶ Information available at: www.avert.org

the number of AIDS cases in the late 1990's, and the slight increase in the number of AIDS deaths in mid 2000 (Figure 4). African Americans tend to have inadequate access to quality health care, and this may in part be able to explain the difference in AIDS cases between whites and African Americans. In the U.S.A HAART is available from private health insurance, Medicare, Medicaid and AIDS Drug Assistance Programs (ADAP). White Americans in need of HAART are more likely than other race groups to have private health insurance; and individuals with private health care are most likely to be using HAART (Bernell and Shinogle, 2005).



Source: Centre for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 2003 (Vol.15)

Figure 3: *Estimated AIDS deaths in the U.S.A (1985-2003)*

Proportion of AIDS cases, by race/ethnicity and year of diagnosis, 1985–2002, United States of America

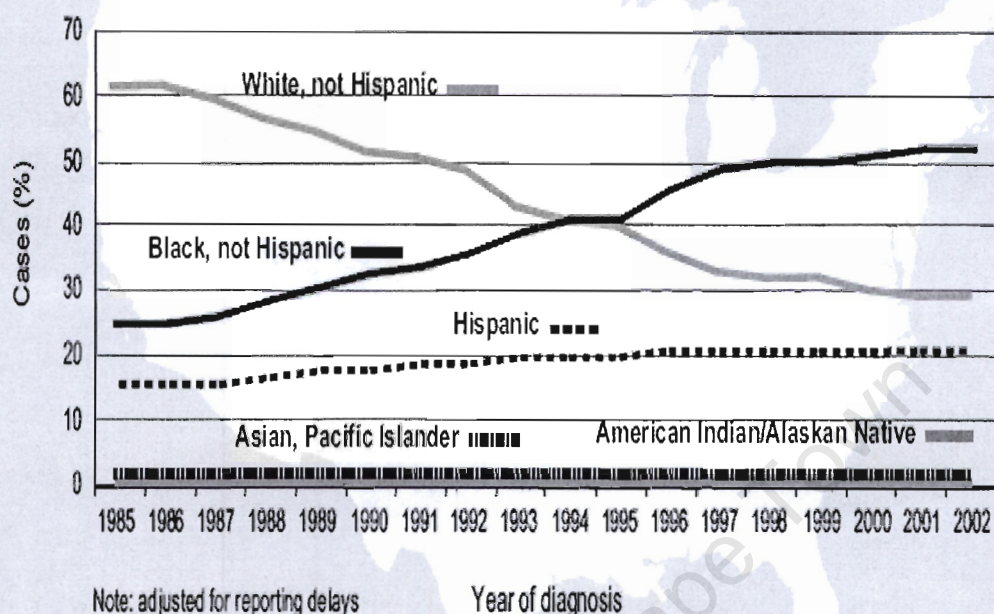


Figure 4: AIDS cases in the U.S.A, by race/ethnicity (1985-2003)

In the U.S.A most patients in need of HAART have access to treatment, while in South Africa, access to treatment is still largely limited to a privileged few. Prior to April 2004, HIV-positive individuals in South Africa could only access antiretroviral treatment through private medical aid schemes, through workplace programmes run by some large companies, through research projects and through NGO-funded interventions such as the international non-governmental organisation Médecins Sans Frontières (MSF) clinics in Khayelitsha, Cape Town. Access to antiretroviral treatment for South Africans who needed it was the exception rather than the norm. Given the positive correlation between poverty and HIV transmission in Africa (Stillwaggon, 2000), and the fact that in South Africa the unemployed are twice as likely to be poor as opposed to the employed (Seekings, 2003), it meant that the unemployed

who most likely needed antiretroviral treatment were least likely to have access to it. Employment and income created a “treatment-divide” that prevented many poor and unemployed infected South Africans who needed treatment, from accessing HAART.

When cheaper generic drugs became available, this gave developing countries the opportunity to have greater access to antiretroviral drugs. South Africa was however slow to exploit the benefits of generic drugs and it lagged behind other developing countries at a similar level of per capita income (such as Botswana and Brazil) in developing a national programme to provide comprehensive care for HIV-positive individuals (Nattrass, 2005). In 2001 Botswana was the first Southern African country to implement a national plan that offered a total package of comprehensive treatment that included providing antiretroviral treatment through the public health system (UNAIDS, 2003). In 2001 such a comprehensive package of care was still nowhere in sight for South Africa. The South African government was criticised for the sluggishness with which it developed a response of treatment and care for people living with HIV/AIDS that included the provision of antiretrovirals (Baleta, 2004; Nattrass, 2004). Until 2003 the South African government continued to justify not making antiretrovirals publicly available by citing cost factors and implementation complexities (Nattrass, 2004a). There were concerns that antiretroviral therapy could not successfully be provided in poor countries because of the high cost of medication and the lack of infrastructure necessary to deliver treatment effectively.

In February 2000 the MSF and the Health Department of the Province of the Western Cape initiated a programme to demonstrate the feasibility of publicly providing antiretroviral treatment in South Africa. The MSF entered into an agreement with the Brazilian government

that allowed the MSF to purchase generic drugs produced by FarManguinhos⁷ at half the price charged by multinationals at the time. The MSF obtained authorisation from the South Africa Medicines Control Council to use the generic versions of Zidovudine (AZT), Lamivudine (3TC), co-formulated AZT/3TC and Nevirapine produced by FarManguinhos⁸. The MSF first line regimen consisted of a combination of two Nucleoside Reverse Transcriptase Inhibitors (viz. Stavudine and Lamivudine) and one Non-Nucleoside Reverse Transcriptase Inhibitors (viz. Nevirapine or Efavirenz). The MSF's first line regimen is identical to the first line regimen that is publicly available in South Africa (Department of Health, 2004a). The second line regimen is a combination of the two NRTI's Zidovudine and Didanosine and the NNRTI Lopinavir or Ritonvir (MSF *et al*, 2003b).

The MSF pilot programme was established in Khayelitsha to provide a test case for exploring the challenges of providing HAART in a poor urban community in a developing country.

Background on Khayelitsha Residents

Khayelitsha is an informal settlement in Cape Town, South Africa. It is Cape Town's largest African township and is home to many unemployed people. According to Census 2001 only 34 percent of Khayelitsha residents are employed and approximately 98 percent of households in Khayelitsha earn a monthly income between R0-R3,200.

Earlier analyses by Coetzee and Nattrass (2004) looked at comparative statistics from the MSF sample and a sample of African adults aged 20 to 59, using the Khayelitsha/Mitchells Plain 2000/1 survey. This analysis enabled us to see how the socio-economic situation of

⁷ FarManguinhos is part of a public research body funded by the Brazilian government.

⁸ Information available at: www.msf.org/search/index.cfm, accessed 1 May 2005)

people in the MSF HAART programme compared to that of the broader population of Khayelitsha residents. The analysis by Coetzee and Nattrass (2004) used a rather broadly defined comparison group. The current analysis builds on Coetzee and Nattrass' (2004) earlier work by using a comparison sample drawn from the KMP sample that was 'matched' to the respondents in the MSF programme by gender and education. The comparison sample was constructed using a representative sample of Khayelitsha residents who were interviewed as part of the Khayelitsha/Mitchells Plain survey of 2000/1⁹. This comparison sample helps to better locate the MSF respondents within a broader socio-economic context.

In the latter half of 2000 researchers from the University of Cape Town (UCT) surveyed 2,644 adults (aged eighteen years and older) in the Mitchell's Plain magisterial district of Cape Town. The main objective of the study was to probe labour-market behaviour, socio-economic characteristics and social/political attitudes amongst working class people.¹⁰ The Mitchell's Plain magisterial district was chosen because it is composed of Mitchell's Plain, a predominantly working class 'coloured' (i.e. mixed race) suburb, as well as the major African townships of Khayelitsha, Langa, Gugulethu, Nyanga and Crossroads. Sixty-nine percent of respondents were African, thirty percent were coloured (with the remaining one percent comprising insignificant numbers of white and Indian people). According to Magruder and Nattrass (2005), over half (52 percent) of African respondents in the survey (966 individuals) were living in Khayelitsha, which is the biggest African township in Cape Town (Figure 5).

⁹ I would like to acknowledge the following people who were involved in the design and implementation of the Khayelitsha Mitchell's Plain Survey (Murray Leibbrandt, Nicoli Nattrass, Dudley Horner, Jeremy Seekings, Owen Crankshaw, Francis Wilson and Kermit Anderson).

¹⁰ See Nattrass (2002), Seekings (2002), and Walker (2003), Skordis and Welch (2002), Schöer (2004) for analyses of labour-market behaviour and social attitudes using this innovative data set.

Figure 5: Map of Khayelitsha



In 2004 researchers from the Centre for Social Science Research at the University of Cape Town decided to revisit the Khayelitsha residents from the original Khayelitsha/Mitchell's Plain 2000/1 survey, in order to observe how their labour market and health status had changed over time. Despite the fact that the original study was not designed as a panel study, and that no attempt to track the respondents had been made in the intervening four years, attrition was reasonably low when compared with that for other developing country surveys (see Lee, 2003). Attrition in the sample of Khayelitsha residents, who had lived in Khayelitsha for at least four years, was 29 percent (Magruder and Nattrass, 2005)

Magruder and Nattrass (2005) tested whether there were systematic differences between mean estimates for key socio-economic characteristics by type of attritor: those who were known to have moved away; those who lived in households that were lost to being revisited and those who attrited for other reasons. This analysis determined that (within a 95% confidence interval) there were no statistically significant differences in mean age, the proportion who were men, the mean percentage living in shacks, mean household income, mean individual income, or the percentage of people in different labour-market states, between the different types of attritors. A two-sample t-test for whether there were systematic differences between mean estimates for key socio-economic characteristics between attritors and non-attritors revealed that there were significant differences in monthly household income, household size and whether or not the individual lived in a shack. Respondents from households with a lower average monthly household income, from households with fewer household members, and who lived in shacks were more likely to attrit.

In the current study the main objective of utilising the Khayelitsha/Mitchell's Plain 2004 Panel survey was to conduct descriptive analysis for respondents who were matched to respondents in the MSF programme. The objective of the descriptive analysis is to locate the respondents in the MSF programme in the general Khayelitsha population. The attrition bias reported in the Khayelitsha/Mitchell's Plain 2004 Panel survey, due to factors such as household size and housing type are considered incidental for the descriptive analysis that follows.

The comparison sample for the MSF respondents was selected from non-attriters in the Khayelitsha/Mitchell's Plain 2004 Panel survey, which as discussed above, may be considered a representative sample of the Khayelitsha population for the analysis that follows. The two hundred and sixty one respondents in the MSF sample who were interviewed at least once were matched to individuals in the Khayelitsha/Mitchell's Plain 2004 Panel survey by gender and education.

The matched data set was obtained the following way¹¹. First we appended the two data sets and created a new variable called 'in program' which took a value of 1 if the respondent was in the MSF data set, and a value of 0 if the respondent was in the Khayelitsha/Mitchell's Plain 2004 Panel data set. We then ran a probit regression (on 'in program') using gender and education as explanatory variables. This regression produced a predicted value for all respondents (MSF and Khayelitsha) – i.e. an estimated probability for being in the MSF data set given the model based on gender

¹¹ I am very grateful to Chris Udry, Nicoli Nattrass and Jeremy Magruder who assisted me in refining the matching process for this study.

and education. For each MSF respondent, we selected the closest match (in terms of estimated predicted probability) from the sample of Khayelitsha respondents.

Comparison of MSF sample and Comparison sample

Table 2: *Unconditional Mean Differences, selected variables, the MSF sample (at baseline), and the comparison sample (year 2000)*

<i>MSF Baseline Sample (Visit 1)</i>											
Statistics	Age	Gender	Education	Individual income	Monthly household income	Per Capita monthly household income	Disability grant recipients	Employed	Unemployed (Strict)	Unemployed (Broad)	Non-labour force participant (Broad)
Mean	34.6	0.30	8.62	R697	R1,113	R291	0.72	0.36	0.28	0.33	0.31
Standard deviation	7.2	0.46	4.58	R696	R956	R316	0.45	0.48	0.45	0.47	0.46
<i>Comparison sample (Year 2000)</i>											
Mean	30.3	0.33	9.17	R366	R1,209	R270	0	0.30	0.17	0.27	0.43
Standard deviation	7.7	0.47	2.61	R775	R952	R245	0	0.46	0.38	0.45	0.50
<i>Mean differences between MSF sample and Comparison sample</i>											
Difference	4.3***	-0.03	-0.56	R331***	-R95	R21	0.72***	0.06	0.10***	0.06	-0.12***
t-test	6.62	-0.76	-1.34	5.14	-1.14	0.60	26.12	1.59	2.85	1.43	-2.92
p-value	0.00	0.45	0.18	0.00	0.25	0.55	0.00	0.11	0.01	0.15	0.01

The t-test is a two-sample t-test with unequal variances. *indicates significance at the 10% level and ** at the 5% level. *** at the 1% level

As shown in Table 2 there were no significant differences between the two samples with regard to education and the proportion who were women. This is to be expected given that the comparison sample was designed to 'match' these characteristics of the MSF sample. More interesting is the fact that there was no significant difference in monthly household income, per capita monthly household income and employment status. Another interesting finding is that labour market participation was higher, rather than lower in the MSF sample.

Looking at the average level of education in the baseline MSF sample, the mean level of education is a Grade 8. One would expect that an average individual in a general population with a Grade 8 level of education should be aged fourteen, given that the average age for enrolment in grade 1 is seven. As a result of matching the gender and average level of education of respondents in the MSF sample with individuals in the general population, the MSF respondents are matched with younger respondents. The age distribution in the MSF sample is 21-59; in the comparison sample the age distribution is 18-55. The difference in average age between the two samples is four years. Even though the difference in average age between the two samples is statistically different, respondents in both samples are in the same phase of adulthood, their early thirties (Table 2).

It is interesting to see that respondents in the baseline MSF sample earn an average monthly income (which is a composite of income obtained from employment, grant income and remittances received) that is R331 greater than the average monthly income earned by respondents in the comparison sample. Given that employment between respondents in the two samples are comparable (Table 2); the difference in individual income is most likely the result of the significant difference in disability grant recipients in the two samples. Table 2 indicates that at their first visit, seventy-two percent of MSF respondents were recipients of disability grants, while no respondents in the comparison sample received a disability grant in 2000. There were one hundred and seventy respondents in the comparison sample earning no monthly income, while only thirty-three respondents in the MSF sample were earning an income of zero at their first visit. This difference in the number of respondents in the comparison sample

who do not earn an income, might also explain their significantly lower average income.

If the strict definition of unemployment is used (i.e. including only active job seekers in the definition of unemployment), there are significantly more individuals in the MSF sample who are of working age and looking for work than there are in the comparison sample. However, if the broad definition of unemployment is used (i.e. including those who say they want to work but are not looking for it actively), the unemployment rates between the two samples are comparable. There are also significantly more non-labour force participants in the comparison sample as opposed to the baseline MSF sample (Table 2). This suggests that people starting HAART are not more likely than other Khayelitsha residents (matched by gender and education) to consider themselves incapable of work. Indeed, they are more likely to be wanting work and looking for it at the time that they started HAART. Nevertheless, given that they are likely to be experiencing improved health subsequently (i.e. in the months following the start of HAART), it seems likely that labour market participation in this sample will rise further.

The MSF programme

Almost a year after its inception, in May 2001, the MSF clinics in Khayelitsha became the first public sector service to provide antiretroviral therapy in South Africa. The programme has achieved positive clinical improvements for people in need of treatment in Khayelitsha (MSF *et al*, 2003b). Coetzee *et al* (2004) conducted an adherence study of the patients included in the MSF programme. Sixty percent of patients started

treatment on Stavudine, Lamivudine and Efavirenz, and thirty-eight percent on Stavudine, Lamivudine and Nevirapine. The Coetzee *et al* (2004) study determined that after 24 months on HAART there were 38 deaths and all the deaths occurred before 12 months on treatment. The majority of deaths were due to the advanced nature of the patient's disease when they started treatment. There were 20 patients who experienced continued deterioration in health even after initiating treatment. The median CD4 lymphocyte count of the patients who experienced disease progression and died was 7 CD4 cells/mm³ and their median duration on HAART was 21 days. A CD4 count of 7 CD4 cells/mm³ is extremely low given that a normal count in a healthy, HIV-negative adult is usually between 600 and 1200 CD4 cells/mm³ (but it can vary). Patients initiating HAART with CD4 lymphocyte counts this low are at a very great risk of experiencing disease progression and death (Egger *et al*, 2002 and Wood *et al*, 2003). Figure 11 represents the survival estimates from the Coetzee *et al* (2004) study. Patients who initiate treatment with a CD4 lymphocyte count of less than 50 have an improved probability of survival after surviving the initial ten months of treatment. The Kaplan-Meier survival estimates of patients who initiate treatment with a CD4 lymphocyte count that is greater than or equal to 50 appear to stabilise after seven months of treatment. The median weight gain at 6 months on treatment was 5.0 kg and after 12 months of treatment it was 9.0 kg. Twelve patients (4 percent) had to change their entire regimen due to treatment failure at the end of July 2003.

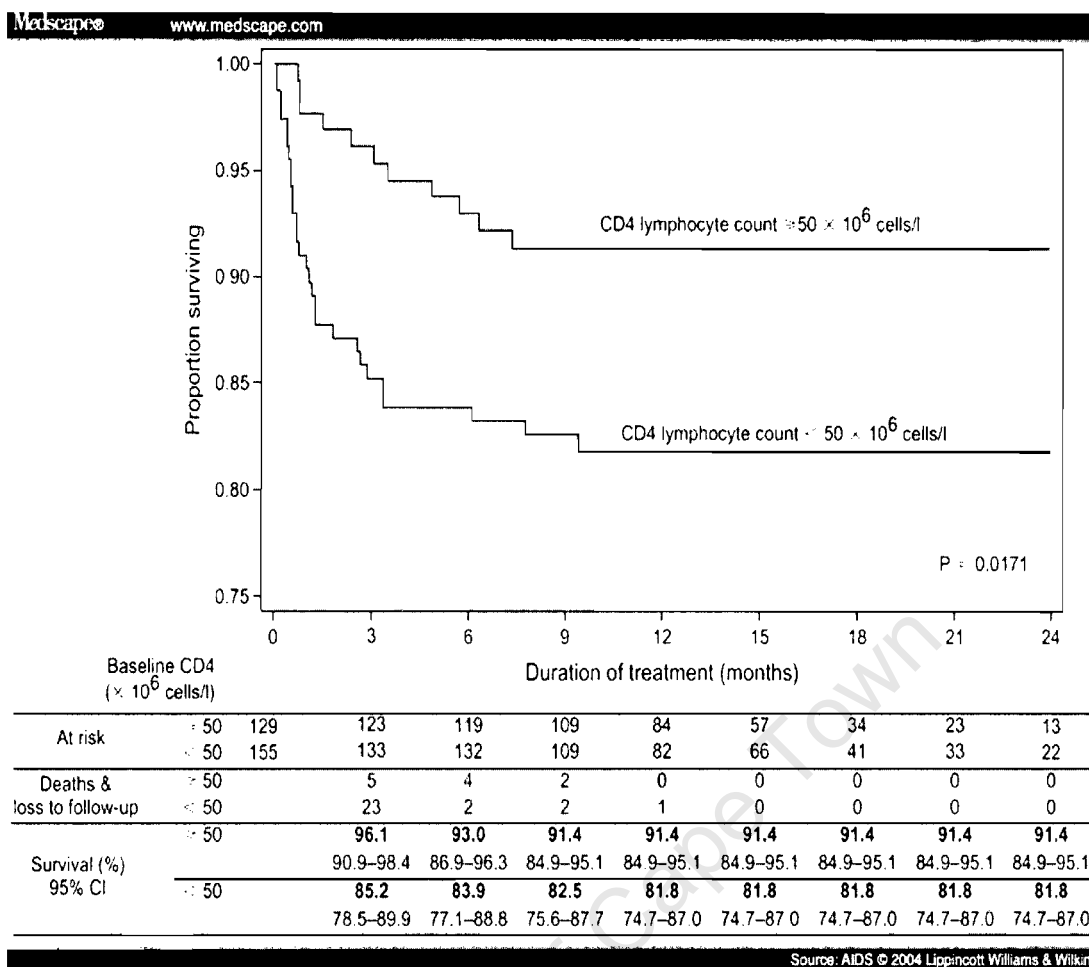


Figure 6: *Survival of adults on antiretroviral treatment, stratified by initial CD4 lymphocyte count*

The MSF project effectively proved that it is feasible to provide antiretroviral treatment successfully in a resource poor setting and achieve significant improvements in clinical health. The MSF experience is similar to Farmer's (2001) experience, in poor rural Haiti. In both Farmer's (2001) and Coetzee *et al's* (2004) study, patients receiving HAART experienced striking improvements in their health. After starting treatment patients suffering from chronic ill health and weight loss experienced notable weight gains and reduced morbidity.

The combination of domestic and international pressure, court action by the Treatment Action Campaign (TAC), and the success of the MSF programme eventually forced the South African government in August 2003 to announce that it would support a national treatment plan for AIDS through the public sector. In November 2003 the government developed an Operational Plan to provide antiretroviral treatment in the public sector. On 1 April 2004 the government announced that it would rollout antiretroviral treatment in 27 pilot sites in four of the nine provinces (Baleta, 2004). According to the TAC (2004) at the end of January 2005 an estimated 32,302 patients were receiving antiretroviral treatment, representing only 16 percent of the target set in the Department of Health 2003 Operational Plan. Table 3 indicates that the rollout of treatment in every province but the Western Cape has been slow and well below targets set in the Operational Plan. The large number of patients on HAART in the Western Cape is largely due to the MSF programme in Khayelitsha.

Table 3: *Comparison of national targets versus actual number of patients receiving ARV's (December 2004)*

Province	Operational plan target 2004/2005 ¹²	Reported number of patients on antiretrovirals ¹³
Eastern Cape	15,626	3,739
Free State	11,883	1,115
Gauteng	45,000	9,691
KwaZulu Natal	74,208	6,086
Limpopo	21,494	935
Mpumalanga	10,767	936
Northern Cape	2,492	515
North West	10,426	2,625
Western Cape	5,728	6,660
Total	197,624	32,302

Source: TAC document 'National ARV Rollout Progress as of December 2004'

The strong connection between unemployment, poverty and HIV transmission meant that while the government dragged its feet to make antiretroviral treatment publicly available, the HIV/AIDS epidemic ravaged the individuals most likely to be unable to access treatment either privately or through employers i.e. the poor and unemployed (Nattrass, 2004a). The provision of antiretroviral treatment in the public sector has built a bridge for the poor and unemployed to cross the "treatment divide" that exists in

¹² See Table 16.9 at page 248 of the Operational Plan 'Expected total number of cases of ARV treatment by province

¹³ Treatment action campaign Document 'National ARV Rollout Progress as of December 2004'.

Information accessed on 20 March 2005 at <http://www.tac.org.za/Documents/ARVRollout/arvstats.htm>

South Africa. However the rollout has been slow and the promise is still more of a hope than a reality.

The purpose of this study

“The happiness of men consists in life. And life in labour”

Leo Nikolaevich Tolstoy

Tolstoy’s quote is an apt place to start considering the impact of AIDS. In the absence of HAART, HIV/AIDS has the capacity to steal peoples’ happiness, their labour and ultimately their lives. An HIV-positive diagnosis is always a major negative life event. Individuals have to cope with redefining themselves as living with a chronic illness that requires burdensome treatment for the rest of their lives. Olley *et al* (2003) studied 149 South African men and women, all of whom had been diagnosed HIV-positive within a year of the study, and found that 34.9 percent of this sample developed major depression. A meta-analysis of 10 international studies that compared rates of major depressive disorder among HIV-positive and HIV-negative individuals, with a total of 2,596 participants, found that HIV-positive individuals were nearly twice as likely to develop major depressive disorder when compared to their HIV-negative counterparts (Ciesla and Roberts, 2001). An American study by Evans *et al* (2002) of HIV-positive women determined that increasing viral load is associated with a greater risk of depression. Depression can arise as patients begin to experience greater HIV-related morbidity. Hays *et al* (2000) found that disease progression, with the accompanying deteriorating physical functioning, is attended by poor emotional well being. HIV infected individuals are particularly vulnerable to experiencing poor emotional well-

being shortly after being diagnosed when HIV-related symptoms first appear, and in the later stages of disease when physical functioning begins to be impaired, and after suffering multiple AIDS-related losses in their social network (Siegel and Lekas, 2002). It is worth noting however, the link between depression and HIV/AIDS is complex; factors that increase susceptibility to HIV infection may also increase risk of experiencing depression. For example, women who are sexually abused face a greater risk of HIV infection, but being sexually abused increases the risk of experiencing depression even among HIV-negative women (Gielen *et al*, 2005).

Physical illnesses, particularly those that are debilitating and life threatening, may be associated with increased suicide risk. A Norwegian study by Hem *et al* (2004) of 490,245 patients diagnosed with cancer determined that cancer patients have a risk of suicide that is 1.6 times greater than the general population, and the risk of suicide was greatest after diagnosis, and decreased over time. The study by Gielen *et al* (2005) similarly found that among HIV-positive women, those who had been most recently diagnosed (within 4 years) had the highest rates of suicidal thoughts. Feelings of hopelessness, isolation because of fear of stigma, disease progression, loss of physical functioning, sexual orientation (particularly being homosexual), abuse, depression, and lack of support if social networks are eroded when friends and family die of HIV/AIDS, are some factors that elevate the risk of suicide for persons living with HIV/AIDS (Hedge, 1990; Pugh and O' Donnell, 1993; Rabkin and Remein, 1993; Marzuk *et al*, 1997; Chandra, Desai and Ranjan, 2005; Gielen *et al*, 2005). The range of factors that correlates HIV/AIDS with contemplating suicide reflects how health status and other spheres of life and well being (i.e. mental, social and emotional) are all intertwined.

HIV steals individuals' labour because in the absence of antiretroviral treatment HIV/AIDS negatively impacts labour productivity. A Canadian study by Auld (2002) of a group of HIV-positive patients on HAART found that being diagnosed HIV-positive decreased the probability of employment by 25 percent. Fox *et al.*'s (2004) retrospective study of tea pluckers in Kenya who had died of AIDS (none of whom were receiving HAART) found that in the last 365 days before they died (relative to a comparative group of tea pluckers) farm workers who died of AIDS were: absent from the job 31 days more; on average plucked 7.1kg percent less tea per day; and spent 22 more days on less strenuous non-plucking duties. In the absence of HAART the progression of HIV disease reduces workers' productive capacity, increases absenteeism, forces them to give up their jobs and ultimately results in their death (Nandakumar *et al*, 2000; Drimie, 2002; Vass, 2002; Rosen *et al*, 2003).

After debilitating individuals and stealing their happiness and their labour, HIV/AIDS steals their lives. Prior to the development HAART a HIV-positive diagnosis forced individuals to adjust the plans they constructed for their future in order to accommodate living a life that would most probably be shorter. HAART has the ability to restore the happiness, life and labour that HIV/AIDS steals. HAART grants people living with HIV/AIDS an opportunity to experience reduced morbidity (i.e. ill-health) and mortality (i.e. death), and revise plans for the future to accommodate the prospect of living longer lives (CASCADE collaboration, 2003; Coetzee *et al*, 2004).

An American study by Brashers *et al* (1999) used focus groups of individuals who were living with HIV/AIDS and receiving antiretroviral treatment to explore the uncertainty that accompanies treatment. In Brasher *et al*'s (1999) study, before initiating HAART, patients made decisions in preparation of death. They quit their jobs, drafted wills,

planned their funerals and in some cases even charged their credit cards to the limit. Once patients started receiving HAART and experiencing improvements in their health, they had to shift from preparing to die to planning for their future. An important decision that patients face when planning for their future is whether or not to return to work. Prolonged life due to HAART necessitates that patients plan in order to ensure a financially secure future. Career planning and planning for pension benefits are once again a part of an HIV positive individual's reality. As Rabkin *et al* states:

"The issue of employment, which often appeared to be peripherally relevant in earlier days of the HIV epidemic, has now assumed a central place in the thinking of HIV+ people whose health has been restored or stabilised by active antiretroviral therapy".

Rabkin et al, 2004, p. 72

As touched on above, HAART may have a positive psychosocial impact because it can reduce mental, physical and emotional distress. But HAART may also be associated with negative psychosocial changes. HAART may contribute to psychosocial deterioration through introducing new stressors into the lives of people living with HIV/AIDS. HAART can introduce stress related to: the need to maintain a high level of adherence to medication regimens; having to attempt to manage the adverse side effects that may result from HAART, and of tolerating the uncertainty regarding how long one will continue to benefit from HAART medications (see below). Furthermore, in the era of HAART, individuals may continue to confront stressors that predated HAART, such as stigmatisation of AIDS and the possible traumas associated with disclosure of their HIV status to others.

According to “Uncertainty in Illness theory” (Mishell, 1998, 1990 in Brashers, 1999), renewed health as a result of HAART can be accompanied by uncertainty. This theory states that patients that have chronic and acute illnesses often experience uncertainty relating to various aspects of their life when they have improvements in their clinical health. This uncertainty is the result of ambiguous symptom patterns, complex systems of care and treatment, insufficient information about diagnosis and unpredictable disease progression and prognosis (Brashers, 2001). Brashers *et al* (1999) found that uncertainty specifically related to the lack of information regarding the long-term effects and efficacy of HAART, the unpredictable nature of individual response to treatment, the potential to develop drug resistant strains of the virus and uncertainty related to financial security in the future was common among patients in their study. Any optimism that patients may experience, with regards to experiencing miraculous improvements in their health, may be tempered by these uncertainties.

Wariness of being hopeful about the future is supported by Lee *et al*'s (2002) study, which found that patients receiving HAART felt that they could only build a tentative future because they believed that their restored health was fragile. Some HIV-positive individuals receiving HAART even feel that they have no control over their health and that good health is simply due to chance (Siegel and Schrimshaw, 2005). This fear - that the renewed health that antiretroviral treatment provides may not be sustained - is similar to the fear that cancer patients receiving chemotherapy experience regarding the recurrence of cancer¹⁴. Individuals receiving HAART who experience improvements in their health may believe that they are hanging onto life by a single horsehair. In the Lee

¹⁴ In cancer patients this fear is called the 'Damocles Syndrome' because in Greek mythology, Damocles was invited to dine with a king and was seated beneath a sword suspended by a single horsehair (Bashers, 1999).

et al (2002) study, patients receiving HAART felt that their renewed health was simply a stay of execution, and death always loomed over their lives.

HAART is an aggressive treatment to treat an aggressive disease. Almost all patients who start antiretroviral treatment will experience nausea, vomiting and diarrhoea early in treatment, but these side effects are usually transient. Some HAART-related side effects are bone-marrow suppression, lipodystrophy syndrome (peripheral fat loss and central fat accumulation) fatigue, headaches, nightmares, insomnia, impaired concentration and drug hypersensitivity that can manifest itself in skin rashes with or without a fever (Carr and Cooper, 2000). HAART does not cure HIV and patients will have to continue HAART indefinitely and experience side effects in order to preserve clinical benefits.

The ambiguous psychosocial impact of HAART means that individuals will probably change their expectations about their health, about the quality of their lives and the productivity of their labour, but it is unclear whether the change will be positive or negative. This study explores the link between renewed health and renewed opportunities for labour supply experienced by HIV-positive patients receiving HAART. More specifically it analyses how HAART impacts the perceived health of a selected sample of men and women living with HIV over time, and how perceptions of health affects labour supply decisions.

The research hypothesis

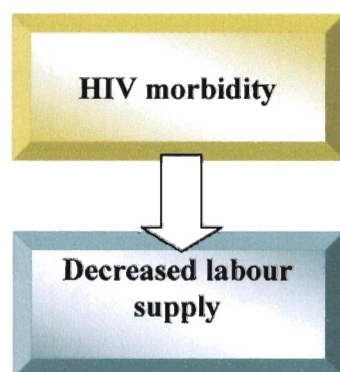
For people with a chronic illness, health rather than labour might become the focal point of their lives. A study by Hickey *et al* (1996) in Ireland found that HIV infected individuals attached less importance to work. This study looked at the self-reported

quality of life of HIV-positive individuals who were outpatients at two Dublin general practices and compared it to the self-reported quality of life of a control group. The control group were healthy individuals living in the same neighbourhood who were matched to infected individuals by age and gender. Each individual reported five areas in their lives that they considered most important and then weighted the relative importance of each life area. Hickey *et al* (1996) found that only 10 percent of infected individuals considered work an important area in their lives, compared to 69 percent of a control group. Unemployment was more prevalent in the study group, and issues related to health and homelessness was notably absent in the control group. It is understandable that a group of healthy individuals who were more likely to be employed emphasised work as a priority in their lives. Hickey *et al's* (1996) suggest that the priorities of HIV-infected individuals can be markedly different from their healthy peers. Living with a chronic disease can make health a central aspect of one's life, such that health-related issues might overshadow all other aspects of one's life, including work.

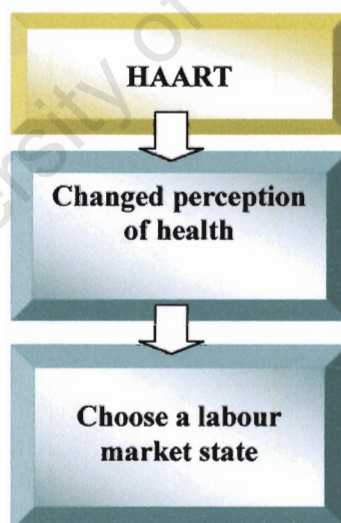
It seems plausible that when patients living with HIV/AIDS and receiving HAART decide whether or not to return to work, their perceptions of their health will influence their decision. If patients believe that the restoration of their health is unsustainable and that they will not be healthy long enough to maintain a job, they might decide to spare themselves the financial cost of searching for a job (i.e. phone calls, transport to interviews, buying a newspaper) and remain out of the labour force. Simply looking for a job can be a stressful exercise, and patients might feel that this stress will negatively affect their already fragile health. Patients might feel that the cost of searching for a job (recurring illness as a result of stress) might be greater than the benefit of income from a job that subsequent ill health might prevent them from maintaining. Patients receiving

HAART who are uncertain about their renewed health would probably be less likely to decide to return to work.

Flow chart 1 Research hypothesis



THEN



Flow chart 1 illustrates the working hypothesis of this study. The hypothesis is that in the absence of HAART, the progression of HIV disease will increase morbidity as

opportunistic infections begin to take their toll. Increased morbidity forces individuals to reduce their labour supply. Eligible individuals initiate HAART and they experience changes in their clinical health, which persuades them to adjust their perceptions of their health. Their perception of their health influences the labour market state that they then choose. To date there is no study that uses longitudinal data to analyse the impact that antiretroviral treatment may have on the labour supply decisions of HIV-positive individuals in a developing country context. This study takes a step towards filling this gap in the research literature by exploring the link between HAART and labour market participation in Khayelitsha, Cape Town.

Why is this topic important?

HIV/AIDS affects individuals, households and communities and is linked to poverty and economic security (see Nattrass 2004a for a deeper discussion on the pathways that link poverty and economic security to HIV/AIDS). The impact of HIV/AIDS can be envisaged as a set of outward radiating concentric circles with the individual at the centre. Analysing the mitigating impact of HAART on the individual may provide insight into the impact that treatment could have on households.

If the caregiver in the household is infected, the progression of HIV-illness will eventually sap the caregiver's energy and prevent him or her from tending to the needs of other household members. HIV disease eventually forces the caregiver to make the transition from being the caregiver or income-earner to being the one in need of care. The household will experience a deficit of labour for cleaning, cooking, caring for children etc. Children may be removed from school in order to care for the sick (Booyesen, 2002; Oni *et al*, 2002). Caring for sick members can be physically and emotionally taxing for both the caregiver and the patient. In the latter stages of HIV

disease people may begin to lose control of their bladder and bowel; require assistance to dress, eat, wash, walk or use the toilet and become wasted and experience pain. It can be unpleasant for the caregiver to see a loved one waste away and humiliating for the patient - who most likely is at an age when he/she should be most virile (Steinberg *et al*, 2002).

Daughters and wives are the ones most likely to accept the burden of caring for the ill. Daughters may be removed from school and wives perhaps forced to work less in order to care for sick household members (Steinberg *et al*, 2002; Oni *et al*, 2002). The burden of care giving, which falls disproportionately on females, will affect gender inequality as women become increasingly dependent on other household members for income. This places young girls and women at risk of contracting HIV, as they will be dependent on others for financial security. Possible future economic constraints (inability to return to work or obtain employment after the death of the patient) may exacerbate poverty, which may prompt these women to engage in 'survival sex' and establish relationships with men in order to meet their material needs (Leclerc-Madlala, 2004). If so, then further fuel will be added to the dynamic linkage between poverty and AIDS.

If there are no children or unemployed to care for the sick, then employed household members may have to stay home to care for ill household members (Loewenson and Whiteside, 1997). If members have to forgo work in order to care for ill members, household income will be affected. In South Africa poor households are very dependent on income from employment and loss of wage/salary income can push households into poverty (Leibbrandt and Woolard, 1999; Leibbrandt, Woolard and Woolard, 2000; Leibbrandt and Woolard, 2001; Seekings, 2003).

If an employed household member becomes ill and works fewer hours or stops working, the loss of this income can have a significant impact on where the household is located within the income distribution. Oni *et al's* (2002) study of rural households in the Limpopo province found that households that suffered a premature adult death and/or chronic illness associated with HIV/AIDS-related conditions had an aggregate annual income of approximately 35 percent lower than households that had not been affected by HIV/AIDS. Since productive aged individuals are most likely to die because of AIDS, it is common for households to lose the main breadwinner (Bollinger and Stover, 1999). The death of a breadwinner is especially bad for low-income households because these households possess very few resources to sustain household expenditure (Pitayanon *et al*, 1997). Unless there are improvements in household income (i.e. household members gaining employment, receiving grants or remittances) the household will be pushed deeper into poverty when it loses employed members.

HIV/AIDS pushes households into poverty not only through its impact on household income but also by the pressure the disease places on household expenditure. While the household foregoes the income of ill members and members that have to be absent from work to care for the ill, it faces added expenditures related to having an ill member in the household. Households have to purchase medication when an infected member becomes ill. Ill members have to be transported to doctors/hospitals/clinics when they get ill, and the household has to cope with funeral costs when he or she passes away. Poor households have very few resources and added expenditure could crowd out resources for basic needs such as food, clothing, housing and sanitation. Lower food expenditure will put children at risk of higher rates of morbidity and mortality because they are most susceptible to severe malnutrition (Samson, 2002a). Studies have found that households remove children from school not only to care for

the ill but also to cope with rising expenditure and spare the household the cost of school fees (Booyesen, 2002; Oni *et al*, 2002).

In the face of declining income and increasing expenditure, poor households with an HIV-positive member will reduce their savings and increase their borrowings (Bollinger and Stover, 1999; Booyesen, 2002; Oni *et al*, 2002). Some households might even sell their assets as a means of coping with the burden of morbidity and mortality (Booyesen, 2002). Booyesen's (2002) South African longitudinal study of rural and urban households in which there had been at least one HIV-positive member, found that households sometimes opt to sell assets (mainly appliances such as stoves, television sets, refrigerators, radios or sound systems or vehicles, furniture and livestock) as a means of coping with increasing expenses and decreasing income. Households in this study generally sold assets that were of a non-productive nature (except for those that sold livestock). The only household that sold livestock in the Booyesen (2002) study was located in a rural area. Booyesen (2002) concluded that households in rural areas are poorer than households in urban areas and have less non-productive assets than urban areas, which could explain why these households had to resort to selling livestock in order to obtain money. All the households in the 'richer' urban areas only sold non-productive assets.

Selling assets as a coping strategy may have long-run poverty implications for the household. If the household sells productive assets such as land or livestock it will severely diminish its capacity to recover from the financial strain that HIV disease places on it. Eroding the household's asset base may be permanent if the household is unable to recoup the assets in the future, and this may impoverish surviving household members and create inter-generational poverty. Since the households most likely to sell

productive assets are the poorest households, HIV/AIDS could exacerbate inequality by pushing the poorest households deeper into poverty while richer households might be able to recover from the impact of HIV/AIDS.

HIV/AIDS mortality impacts the composition of households and creates orphans. As the disease progresses and the productive members of the household die, more households will be headed by females, by the elderly or consist of children only. At the end of 2003, UNAIDS *et al* (2004) estimated that there were 1 100 000 South African children under age 17 who had lost a mother, father or both parents to AIDS. Households might be forced to dissolve and orphaned children could be sent to live with different relatives when parents die. Orphans could be sent to live with relatives in different households and lose contact with their siblings.

South Africa's history of the migrant labour system, where both parents might have been working away from home and children were raised by extended family, illustrates that having someone other than the biological parent assume a parenting role need not have a negative impact on a child's development (Bray, 2003). However, AIDS orphans could lose contact with their siblings if they are all sent to live with relatives in different households, when there might be value in maintaining familial ties. To the extent that grandparents caring for their grandchildren depended on remittances from the child's parents, grandparents may face a financial burden when remittances are lost due to the death of a child's parent as a result of AIDS. AIDS orphans might be at a greater risk of experiencing malnutrition. Children who have been orphaned by HIV/AIDS may have to enter the workforce and be vulnerable to being exploited in the workforce (Bray, 2003).

In sum, HIV/ AIDS can create a cycle of poverty that starts with an adult household member falling ill. As HIV disease progresses the patient will be forced to stop working and household income will fall. To cope with the fall in income and the added expenditure related to the infected member's morbidity, savings may decrease, borrowings may increase, assets may be sold and children may be removed from schools. HAART may be able to interrupt the cycle of poverty by restoring the physical, mental and emotional wellbeing of individuals living with HIV/AIDS, and granting them the opportunity to resume their roles as caregivers and income-earners. Children may attain better education achievements because HAART may spare them the emotional distress of having to witness the physical, emotional and mental wasting of a patient, coping with the death of a loved one, and being removed from school in order to care for debilitated household members. HAART may be able to reduce the vulnerability of young girls and women engaging in risky sex in order to survive the long-term effects of losing an income-earner in the household. HAART might allow household members who are not infected to remain in employment because they may not have to be absent from work in order to care for the ill.

The provision of HAART also has epidemiological benefits. According to the latest ASSA model (ASSA2003), South Africa is reaching the peak of HIV incidence and HIV prevalence (see Figure 7). As of 2005, 18.2% of South African adults and 10.6% of the total population was estimated to be HIV-positive. According to the model, only 10% of those needing HAART are actually receiving it, and approximately half a million people are AIDS-sick and in need of HAART.

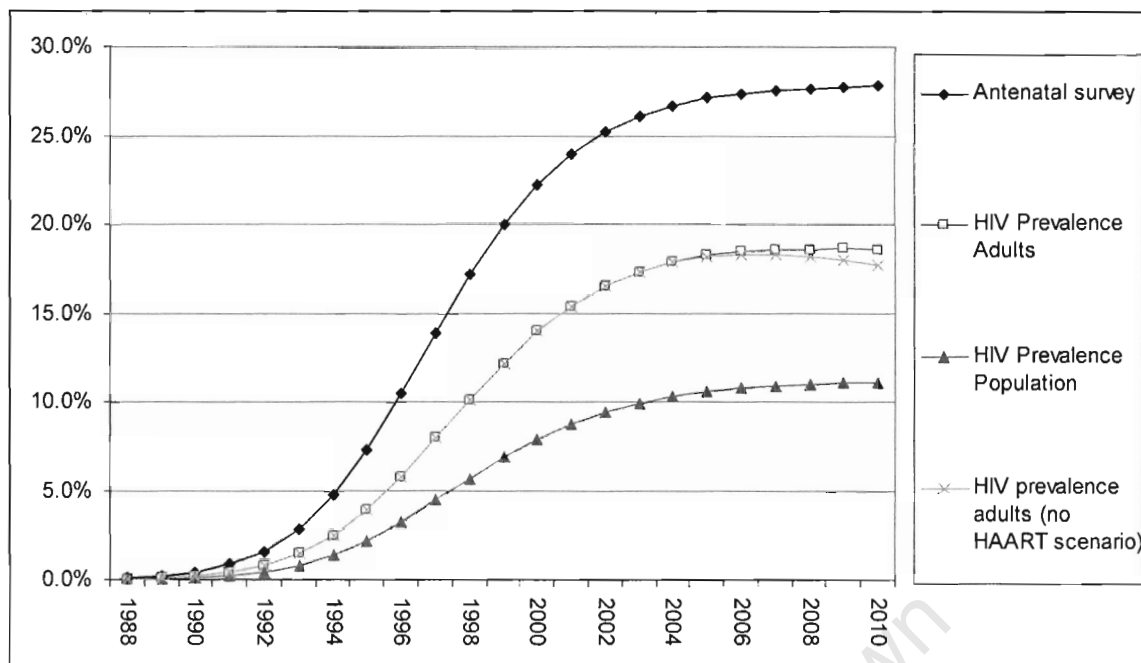


Figure 7: *HIV Prevalence in South Africa. (Source: Projections made from the ASSA2003 Model)*

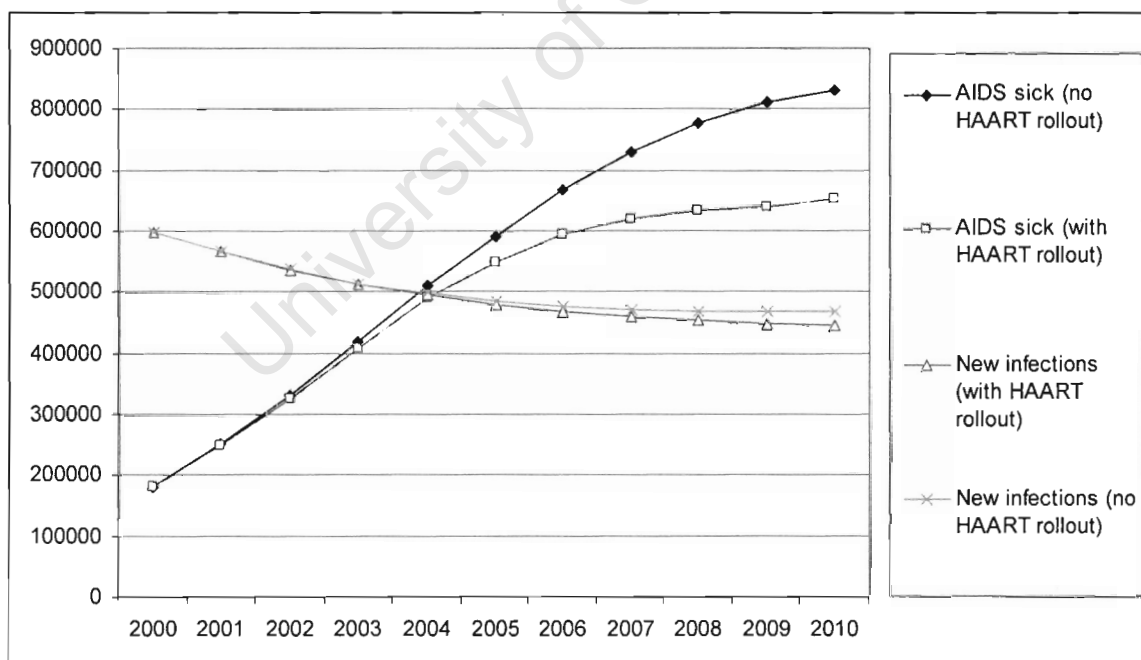


Figure 8: *New Infections and number of AIDS-sick people (with and without a HAART Rollout). (Source: Projections made using the ASSA2003 model)*

The ASSA2003 model assumes that by 2008, 50% of people who need HAART will be receiving it. Although this will raise HIV prevalence in the population (relative to a no HAART scenario – see Figure 7), this is simply because people with HIV are living longer and not the result of greater numbers of new HIV infections. Indeed, the ASSA2003 model estimates that as a result of HAART, there will be *fewer* new HIV infections as a result of the rollout (see Figure 8). This is because people on HAART are less infectious than they would be in the absence of treatment. The model predicts that this preventative effect of HAART outweighs the impact of HIV positive people living longer (and thus having more opportunity to infect others). As a result of HAART there will also be fewer AIDS sick individuals (Figure 8).

Conclusion

In the wake of the South African government's programme to make antiretroviral treatment available in the public sector, there is a need to research the long-term impact that this programme will have on health and labour supply decisions.

As discussed earlier in this chapter, the progression of HIV disease reduces labour productivity. HAART will most likely have an impact on reducing the number of individuals who are AIDS sick. HAART might be able to mitigate the debilitating impact that HIV/AIDS has on individuals' capacity to supply labour. HAART will most likely impact how individuals living with HIV perceive their health, which will most likely inform their labour supply decisions. As a result of living with a chronic disease and receiving HAART, it is likely that the labour supply decisions of patients receiving HAART will differ from those of their HIV-negative counterparts. This study

takes a step towards filling the gap in the research literature, available from developing countries, of the long-term impact that HAART will have on the perceived health and labour supply of people living with HIV/AIDS.

University of Cape Town

The Impact of HAART on Perceptions of Health

Introduction

This chapter explores how HAART affects the perceived health of people receiving antiretroviral treatment. More specifically it addresses the question of how HAART has impacted the perceptions of health, over time, of a sample of HIV positive men and women attending MSF clinics in Khayelitsha. Understanding the association between receiving HAART and perceptions of health is necessary in order to discern the impact that HAART has had on labour supply decisions.

As described in Chapter 1, the hypothesis of this study is that patients that receive HAART are likely to experience an improvement in their clinical health, which most likely will influence how they perceive their health. The supposition of this study is that personal perceptions of health are directly associated with labour supply decisions. It is expected that attitudes related to the sustainability of renewed clinical health will directly inform labour supply decisions. Although clinical information may in some sense be a more objective measure of health status, it is nevertheless the case that deciding whether or not to supply labour probably depends less on clinical health, and more on whether or not an individual ‘feels’ that he or she is healthy enough to supply labour. The following anecdote is illustrative of this issue.

"I treated a patient who tested HIV positive and refused a disability grant even though he had a CD4 count of less 1. He insisted that he felt that he could return to work."

(Personal correspondence with Dr. Anisa Bhattay, 20 October 2004)

The above example refers to a patient classified as Stage 4 AIDS (according to the WHO classification) and not receiving HAART, who wished to remain active in the labour market despite poor clinical health. The experience of this patient indicates the important role that perceptions of health can play in labour supply decisions. Converse to the patient mentioned above, a patient receiving HAART who may be clinically well (i.e. have a relatively good CD4 count), may still feel depressed and anxious, and decide that he or she is not well enough to work.

In this study a self-reported categorical measure of health is used to analyse the impact that HAART has had on perceived health. Unfortunately, due to clinic-level restrictions on the use of data, it was not possible to link this subjective health measure to an objective health measure such as individual CD4 counts. It is not possible to assess whether a patient who has experienced an increase in his or her CD4 count, perceives his or her health to be better than a patient with a low CD4 count. However, it is possible to measure whether over time trends in perceptions of health mirror trends in changes in clinical health in aggregate.

This chapter is arranged in the following manner; the first section provides a description of the data, the second section contains a discussion of the health measure used in the study, the third section explains the model used in the analysis and the final section contains a discussion of the findings of the model.

Data Description

In January 2002 researchers from the MSF and the University of Cape Town embarked on a socio-economic longitudinal study of adults¹⁵ in Khayelitsha who had not been exposed to prior antiretroviral treatment. The study obtained ethical approval from the Health Sciences Research Ethics Committee. Clinical criteria for selection into the MSF programme meant that at baseline patients were very ill. At baseline patients were interviewed and the idea was to re-interview each person on a six-monthly basis in order to explore the socio-economic impact of providing HAART. Patients willingly completed questionnaires and consented to being interviewed. A total of two hundred and sixty one patients had nearly semi-annual health and economic assessments over a period of sixty-four months.

When the MSF initiated their HAART programme in Khayelitsha they were interested in studying: adherence to HAART; the impact of HAART on quality of life; and the socio-economic impact of HAART on their sample of patients. The analysis in this chapter utilises data collected in the socio-economic study. It complements analysis related to the adherence study (Coetzee *et al*, 2004), and the health-related quality of life study (HRQL) (Jelsma, 2003) using the same cohort of HAART patients.

While Coetzee *et al*'s (2004) adherence study focused on the impact of HAART on clinical markers of health i.e. death rates, CD4 counts and viral loads, the current study provides insight into how patients perceive changes in their clinical health. While

¹⁵ I 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 Darder, Toby Kaspar, Eric Goemere, EmiLou MacLean and Nicoli Nattrass. Marta Darder and EmiLou MacLean finalised the survey design and managed the data collection.

Jelsma's (2003) HRQL study described health in terms of many health domains - viz. mobility, self-care, usual activities, anxiety/depression and pain/discomfort - the current study describes health using a general measure of self-reported health. A general perception of health might differ from a health measure that is made up of various domains. When evaluating general health a patient might not consider all the domains included in the HRQL study. Focusing on each domain of health, as the HRQL study does, might make changes in these domains of health salient; poorer health-related quality of life might be reported than if patients simply reported general perceptions of health. However, as the MSF clinic has not agreed to the linking of these different data sets, the current study relies solely on the reported health measure.

The sampling design of the study provides us with panel data, which allows for analysis of changes in health between individuals in the sample, and changes within the sample between successive interviews. Interviews were conducted at the clinics when patients arrived to collect their medication. Patients who were selected into the sample were interviewed on site at three clinics, viz. Michael M, Nolungile and Site B. The structured questionnaire covered a range of socio-economic issues and was available in both Xhosa and English. The interviews were conducted face to face in the preferred language of the respondent. Each person was asked questions about his or her daily activities, household composition, labour-market status, personal income, household income, saving and borrowing behaviour. The questionnaire is included in Appendix A.

Selection into the Programme

When the HAART programme was designed, selection was to be determined according to a set of clinical, behavioural and socio-economic criteria (MSF *et al*, 2003a). Patients had to meet all the selection criteria in order to be included. These were as follows (MSF, 2003a).

1. Clinical Criteria

- World Health Organisation classification of being in Stages 3 or 4 of AIDS, or asymptomatic patients with CD4⁺T cell counts of less than 50/mm³.
- Karnofsky Performance Score greater than 40% (an alternative measure of health status).

2. Biological Criteria

- Two tests confirming HIV serostatus (either ELISA or Rapid tests);
- CD4⁺T cell counts from 0 to 200/mm³;

3. Ability to adhere to therapy

- Attended the clinic for at least three months;
- Presented on time for the previous four visits;
- Able to take medication regularly.

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 HAART;
- Commitment to attend a support group regularly;
- Open about HIV status and ready to commit to long term HAART;
- 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 could perhaps have resulted in the sample of HAART patients manifesting a degree of selection bias. 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 Marta Darder from MSF, the programme has yet to turn away anyone who shows the requisite clinical signs (personal communication). 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) – and in part the result of counselling from the clinic (which helped those who initially did not comply, e.g. because they were late for previous appointments) to mend their ways and thus be accepted into the programme later. No person was turned away because they were judged to be too well off.

This suggests that the sample of HAART 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 HAART 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 young women overwhelmingly dominate treatment programmes (see Table 4). 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 MSF criteria (as these appear to have had no impact in terms of turning potential patients away), but rather a function of exogenous factors – most obviously gender and socio-psychological factors such as the fear of stigma.

University of Cape Town

Table 4: *Baseline descriptive statistics for the study sample*

<i>Sample Size</i>	
Number of respondents	261
Number of observations	569
Median number of interviews	2
<i>Respondent's Demographics</i>	
Female	71%
Male	29%
Average age	34
Average age when diagnosed HIV+	31
Average level of education	Grade 9
Recipient of a disability grant	72%
<i>Household Characteristics</i>	
Average number of household members	4
Percentage living in informal dwellings (shack)	59%
Households with children	59%
Households that have had a child younger than 6	36%
Households that have had a child aged 7-14	42%
Average monthly household income	R 1342
Respondent's average monthly income (wages+grants+remittances)	R 859
Average monthly household income from the respondent's income	77%
Average monthly household income from the respondent's wages	57%

Patients were interviewed between 1 and 5 times. Almost all (98.4 percent) the patients in the sample participated in three or less interviews. Table 4 provides some baseline descriptive statistics related to the study sample. More than two-thirds of the sample (71 percent) is comprised of women. The sample is comprised of Xhosa speaking individuals who are most likely of Xhosa ethnicity. The greater proportion of women in the sample might reflect women being more willing to visit clinics, because they face less stigma attached to clinic attendance than men, since women are expected to visit clinics when they are pregnant and have children (Beck, 2004). Across all 'waves' of the panel study the average monthly income that the respondent receives (which consists of grant, wage and remittance income) is R859. Disability grant income is an important source of income given that 72 percent of respondents are recipients of disability grants. Table 4 can be used to construct a profile of the average respondent in the sample. The average respondent is a 34-year-old female with a grade 9 level of education who receives a disability grant. Her income contributes 77 percent towards the total household income. More than half (57 percent) of the total household income is comprised of her wage income and she lives in a shack with 3 other people, and one household member is most likely a child. This profile suggests that patients in the sample might be important contributors to household income and possibly provide care to children.

Health Measure

The respondents' responses to question B8 (see below) were used to construct a measure of perceived health:

B8: "In the last month, how often did physical disabilities or health problems interfere with your ability to work at a job, look for a job, study, or work around the house?"

The response to this question was a pre-coded rating scale of "*All the time*", "*Most of the time*", "*Some of the time*", "*A little of the time*" or "*None of the time*". Patients' view of their health status was determined according to their response to question B.8. Patients who responded "*None of the time*" were classified as 'not feeling sick'. Those who responded "*A little of the time*" or "*Some of the time*" were classified as feeling 'a little sick'. Anyone who responded "*Most of the time*" or "*All the time*" was classified as feeling 'very sick'. This question measures the subjective experience of morbidity. One could perhaps hypothesise that those who felt sick most of the time did not expect to live very long. Both the experience morbidity and perceived life expectancy are likely to affect labour supply decisions.

In the discussion below, the term 'active' refers to the respondent being able to study, work, look for work or work around the house. Table 5 shows the classification of the patient's perception of their health according to their responses to B.8

Table 5: *Classification of patient's health status according to their response to B.8:*

"In the last month, how often did physical disabilities or health problems interfere with your ability to work at a job, look for a job, study, or work around the house?"

Patient's response to B.8	Classification of Health Status
"None of the time"	Not feeling sick
"A little of the time" or "Some of the time"	A little sick
"Most of the time" or "All the time"	Very sick

Basing the analysis of perceived health on question B.8 could introduce some measurement error into the analysis because 'health problems' and 'physical disabilities' are very broad terms. One weakness of using B.8 as a health measure is that we cannot know with complete certainty what respondents interpret 'disabilities' and 'health problems' to mean when they respond to question B.8. Does the respondent consider a disability and a health problem something that is permanent or transient, physical or emotional? If disabilities and health problems were interpreted as referring to more permanent conditions such as a crippled limb, then B.8 would likely measure long-term health problems. Some of these may fluctuate in severity, for example, a patient might have sustained a back injury many years ago. This patient may have been active for many months but in the month prior to being interviewed done something to aggravate this injury that left him or her bed-ridden for most of the month. To the extent that this disability and health problem are unrelated to the patient's HIV-disease and unrelated to HAART this health change, which would most likely affect reported perceived health, should not be attributed to HAART. Such a case would introduce

measurement error into the analysis because we would not be measuring the impact that HAART has had on changes in perceived health.

This limitation can to some extent be addressed by the fact that a respondent's interpretation of the intended meaning of a question is influenced by the context in which the question is presented (Sudman *et al*, 1996). The ordering of questions in the survey most likely prime the respondent to place health within the context of HIV-related health, so that HIV becomes the salient health problem when answering health related questions. The respondents were asked how long they had been on antiretroviral treatment, what year they found out they were HIV-positive, who they had disclosed their HIV status to, how many days they were too ill to do their normal activities in the last month, whether they lost any income in the last month because of their illness and whether anyone had to take time from work or school to care for them in the last month, prior to being asked question B.8 (see Appendix A). To the extent that the questions preceding B.8 causes HIV disease to become the most dominant health problem in an individual's mind when responding to questions, health will be synonymous with HIV health. Through framing health in the context of HIV disease, B.8 most likely measures disabilities and health problems related to HIV.

Another possible limitation in the health measure is that there is no objective standard for measuring the incidence of ill health that factor into perceptions of disability and health problems. A patient who was ill twice a month may have felt that health *always* interfered with his or her ability to be active; while a patient who was ill five times in the month prior to being interviewed may have felt that health *sometimes* interfered with his or her ability to be active. The linkage between frequency or severity of illness

and ability to be active it is not entirely clear. However, given that we are interested in measuring perceptions of health, the specific clinical health factors that feed into the respondent's perception of his or her health are of lesser importance than the perception itself. The current analysis focuses on health in a very subjective manner because as explained in Chapter 1, it is the perception of health that is relevant to labour supply decisions – rather than objective clinical criteria. If it is reasonable to assume that B.8 adequately measures changes in perception of health as a result of HAART, then it is can be used as the variable of interest in the present analysis.

Transition Data Analysis

The data was arranged in the long form in order to utilise the panel nature of the dataset. The 'long form' for a panel data set arranges data according to personal identifiers and time, so that there is a line of data for each time a respondent was interviewed (rather than just one line of data for each respondent). Reported weeks on antiretroviral treatment denote 'time' in the analysis that follows. Econometric models used in transition data analysis were utilised to probe the interaction between individual characteristics and transitions in perceived health over time.

Transition data analysis is also referred to as duration data analysis because it can be used to study the time period (*duration*) during which the given event did *not* occur. A succinct definition of transition data analysis is the following:

*“Transition data analysis is the analysis of the duration for the non-occurrence of an event during the risk period. **OR** the analysis of rates of the occurrence of the event during the risk period. ”*

Yamaguchi, 1991, p.3

Transition data analysis is a statistical technique that looks at the pattern and covariates of the occurrence of events within an observation period. Transition data analysis examines how covariates affect the length of time between consecutive events. For example, it is able to analyse how having a disability grant affects the length of time that a respondent who does not want to work will continue to abstain from the labour market before making the transition to wanting and looking for employment. The observation period refers to the length of time for which information about all respondents is available. In the current study the observation period is 11 April 2002 to 22 January 2004. An event is defined by some qualitative variable marking an end-point such as: finding a job; the occurrence of death; marriage; birth; divorce etc. An event can also be referred to as a ‘failure’ even though the event of interest may be something positive. The time between successive events are referred to as spells. In the current study an event is defined as a change in self-reported health after the individual has been on HAART.

By definition in order for an event to occur there has to be a preceding time period or *duration* in which the event did not occur. Additionally, an individual can only be eligible to experience an event if there was a period during which they were at ‘*risk*’ of experiencing the event e.g. in order for an individual to be at risk of getting divorced they have to be married. When spells in which the respondent did not have an event are

added together, they are referred to as censored spells. Respondents who experience no transitions before the end of the observation period are treated as right-censored observations. These right-censored observations contribute to the hazard rate with their survival information.

The ‘hazard rate’ represents the instantaneous probability of an event occurring at a particular moment in time during a risk period, *given that the event did not occur previously*. The hazard function $h(t)$ is defined as the ratio of the unconditional instantaneous probability of having the event $f(t)$, divided by the survivor function $S(t)$ which is the probability of not having the event prior to time t . Let T be a random variable for the duration of the risk period for an event. Then the survivor function is given as:

$$S(t) = P(T \geq t)$$

$P(T \geq t)$ indicates that the risk of not experiencing an event continues beyond time t . The unconditional instantaneous probability of having the event $f(t)$, which is also called the probability density function of T , is given as:

$$f(t) = \lim_{\Delta t \rightarrow 0} \frac{P(t \leq T < t + \Delta t)}{\Delta t}$$

From these two functions we can obtain the hazard rate, which is given as:

$$h(t) = \lim_{\Delta t \rightarrow 0} \frac{P((t \leq T < t + \Delta t) | T \leq t)}{\Delta t} = \frac{f(t)}{S(t)}$$

The hazard function indicates the instantaneous probability that the event occurs during the time $(t, t + \Delta t)$ given that the event did not occur prior to time t . The limit for t tends towards zero. The hazard rate is always positive. In other words, the implicit understanding is that if the observation period was long enough we would observe an event.

The hazard is a risk and it may vary with time as illustrated in Figure 9. The hazard may be constant over time $h_3(t)$, increasing $h_1(t)$, decreasing $h_4(t)$, or first increasing and then decreasing $h_5(t)$ or first decreasing and then increasing $h_2(t)$. A hazard similar to $h_5(t)$ might exist for women wanting to have children, if one theorised that over her lifetime a women’s risk of having a child is linked to her fertility. As a child a women’s risk of having a baby starts out low but it increases steadily as she matures. Her risk of having a child peaks between the ages of 17-25, which is her peak age of fertility. After the age of 25 her risk of having a child will start to decline.

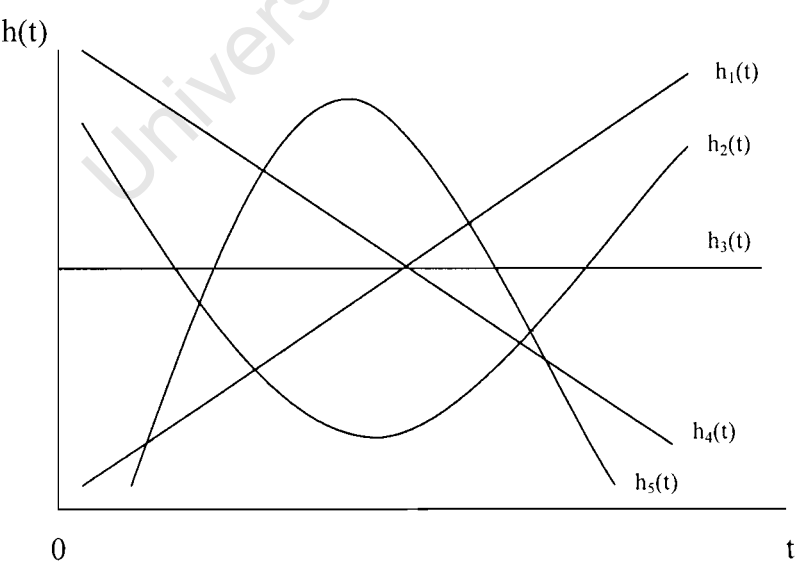


Figure 9: Hazard rates may vary over time

The hazard may vary among groups over time as illustrated in Figure 10. For example, over time men might always face a greater risk of being in a car accident as opposed to women, such that they face a hazard $h_m(t)$, while women face a hazard $h_f(t)$.

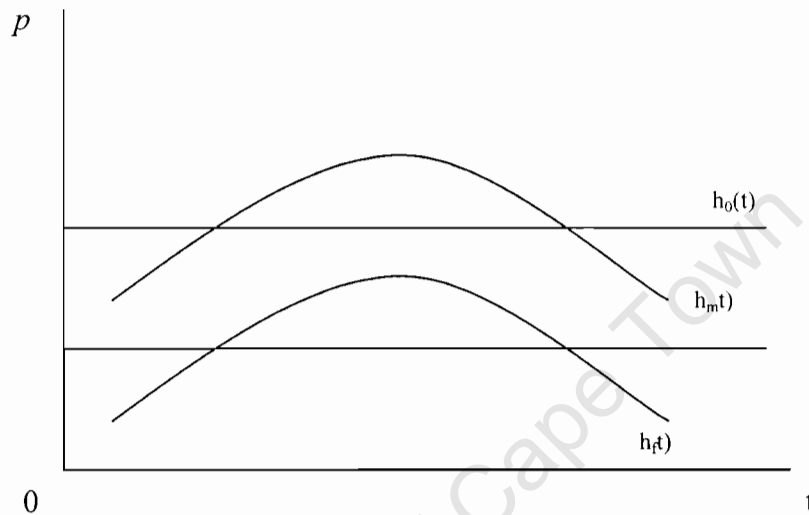


Figure 10: Hazard rates may vary among groups over time

Transition data models were selected to explore the hypothesis that over time HAART will have a positive impact on perceptions of health, because these statistical models take into account dynamic data generating mechanisms (which can change across individuals and over time). In this analysis it means substantively that we expect that the effect of HAART on patients' perception of health will differ significantly over time. We expect that a longer period spent on HAART will result in the patient having a better state of clinical health and a more favourable perception of his or her health. Our statistical model has to incorporate this dynamic expectation and it cannot treat the process of changes in perceived health as a result which happens regardless of how long the patient has been receiving HAART.

Transition data models not only look at how long events last, but also at what happens when they end. We can look at the parameters that in combination, or individually, influence the timing of the event of interest. These models are able to use time-dependent covariates, which is important because we are interested in analysing whether a change in the state of a covariate impacts the hazard of experiencing the event.

Non-parametric estimates (viz. Nelson-Aalen and Kaplan-Meier) were determined for all patients irrespective of subsequent discontinuation of therapy. Kaplan-Meier estimators graph the survival function $S(t)$. Nelson-Aalen estimators graph the cumulative hazard function, which is similar to a count-data interpretation of $H(t)$. Non-parametric analysis, unlike semi-parametric analysis, does not specify the relation between hazard rates and covariates, but obtains hazard estimates (Nelson-Aalen) or survival estimates (Kaplan-Meier) as a function of time.

Semi-parametric analysis uses Cox proportional hazard regression. The Cox model makes no assumptions about the shape of the baseline hazard $h_0(t)$ - the hazard when all covariates are equal to zero - which may vary as illustrated in Figure 9. For Cox models the shape of the baseline hazard is not important but what the model does assume is that whatever the shape of the hazard, it is the same for everyone. One subject's hazard is a multiplicative replica of another's. Leaving the baseline hazard unspecified is advantageous when we are not able to make a reasonable assumption about the shape of the hazard. It is arguable that it is better to assume that the shape of the baseline hazard is the same for everyone than making an assumption about $h_0(t)$ that is wrong. (Cleves, Gould and Gutierrez, 2004).

Stratified Cox estimation relaxes the assumption that everyone faces the same baseline hazard multiplied by his or her relative hazard. The baseline hazards are allowed to differ by group as in Figure 10 but the coefficients are constrained to remain the same (Cleves, Gould and Guitierrez, 2004). Models are stratified (e.g. by 'clinic' in this study – see below) in order to ensure that the effects of the covariates are measured correctly. In the absence of stratification we would obtain inefficient hazard estimates of our transitions with bigger standard errors because we did not utilise all available information in the dataset.

Cox regression results are based on forming, at each failure time, the risk pool or risk set, which is the collection of subjects who are at risk of failure, and then maximising the conditional probability of failure. In Cox modelling the times at which failures occur are not relevant, rather the ordering of failures is important. Cox starts from the conditional probability that the i -th individual leaves the risk pool at t_i , given that there are other individuals that could have left at that point. This conditional probability is defined as a ratio, it is the hazard of person i , divided by the sum of the hazards for all other persons who have not left. Cox orders failures so that we are able to know who fails first and then who is left and available in the risk pool to fail. When subjects are tied (fail at the same time) and the exact ordering of the failure is unclear we need to implement a treatment for the ties (Cleves, Gould and Guitierrez, 2004).

All analysis in the current study utilise STATA SE version 8 software (Stata, College Station, Texas, U.S.A). The Cox models were stratified by clinic to account for any unobserved differences in clinics which might affect perceptions of health. Stratification by clinic was deemed necessary because certain clinics might service

patients who are more ill and in a poorer emotional state than patients presenting at other clinics; the doctors, nurses or counsellors at a certain clinic might also be more capable of treating patients who present at a time when they are very ill and in need of counselling; and the relationship between HIV-positive patients and their physicians can affect optimism related to health (Solomon *et al*, 2002).

The Cox models in the current study use the Breslow method for handling ties. One-way transitions were analysed for univariate and multivariate models. All econometric analysis estimated models that included all conceivable, testable influences for the transition under investigation.

For the purpose of the current analysis, respondents who were only interviewed once were treated as 'deaths'. This assumption was made because an explanation for the lack of follow up interviews was unavailable. In total sixty-five respondents are assumed to have died. Of course not all these patients necessarily died. Some may have simply left the programme or moved. However, our assumed number of 'deaths' is only slightly higher than the number of deaths reported in the adherence study of these same patients by Coetzee *et al* (2004). This implies that the overall majority of our 'deaths' were in fact real deaths.

Adherence study

Coetzee *et al* (2004) used survival data analysis to assess the clinical impact of HAART. All the patients included in Coetzee *et al's* (2004) study had no previous exposure to antiretroviral treatment. The patients in the Coetzee *et al* (2004) study

received HAART for a median period of 13.9 months and within twenty-four months there were thirty-eight deaths. All the deaths occurred before twelve months on treatment. The median duration on HAART for the patients who died in the Coetzee *et al* (2004) adherence study was twenty-one days. The majority of deaths were due to the advanced nature of the patient's disease when they started treatment. There were twenty patients who experienced continued deterioration in clinical health even after initiating HAART. The median CD4 lymphocyte count for patients who experienced deteriorating clinical health was 7 CD4 cells/mm³. A CD4 count of 7 CD4 cells/mm³ is extremely low given that the normal count in a healthy HIV-negative adult is usually between 600 and 1200 CD4 cells/mm³ (but it may vary). Patients initiating HAART with CD4 lymphocyte counts this low are at a very great risk of experiencing disease progression and death (Egger *et al*, 2002; Wood *et al*, 2003).

Coetzee *et al* (2004) determined that patients receiving HAART with a baseline CD4 count of < 50 CD4 cells/mm³ had an 81.8 percent cumulative probability (risk over time) of remaining alive at 24 months. The cumulative probability of remaining alive for patients with a baseline CD4 count of > 50 CD4 cells/mm³ was 91.4%. Patients in another Cape Town based study who had CD4 counts of < 50 CD4 cells/mm³ and were not receiving HAART were on average expected to survive less than 12 months (Post *et al*, 1996). HAART dramatically reduced mortality because in the absence of treatment more than half of the patients in Coetzee *et al*'s (2004) sample would have died within 24 months.

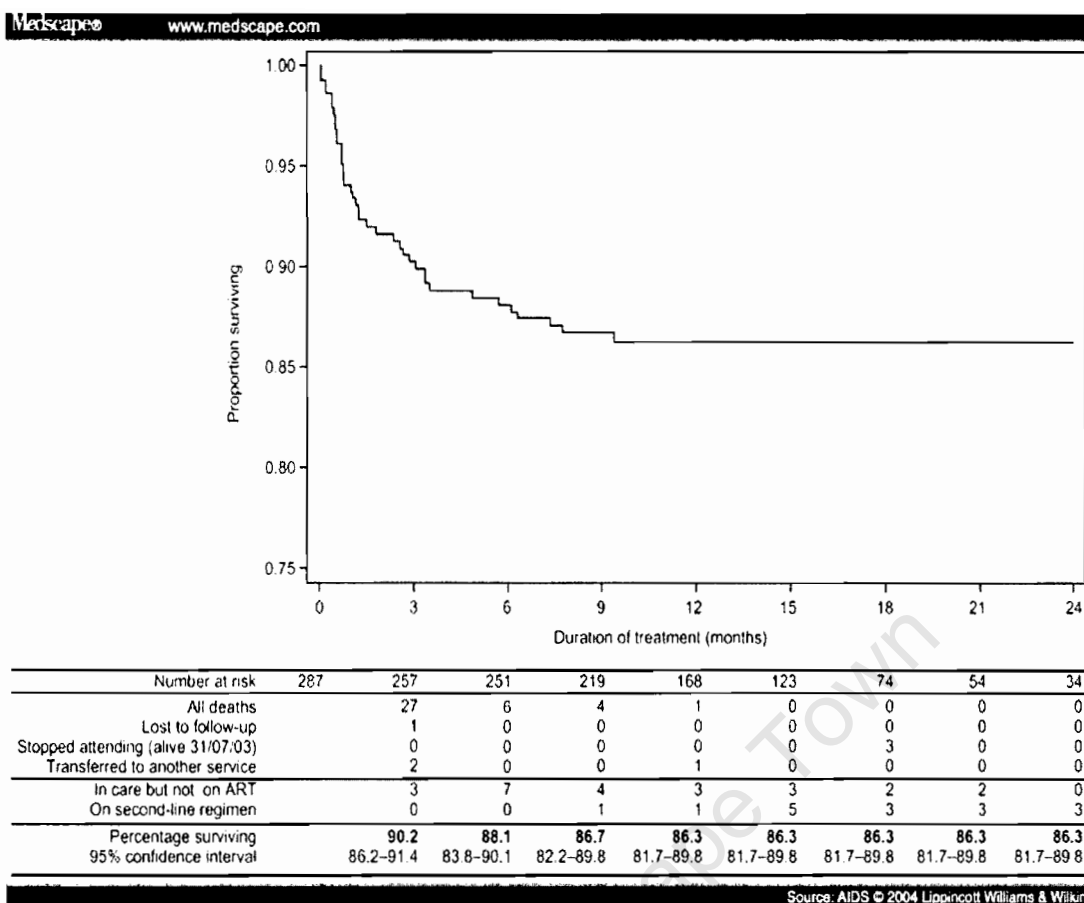


Figure 11: *Survival of adults on antiretroviral treatment from Coetzee et al's (2004) adherence study*

In *Coetzee et al's* (2004) study, after approximately 10 months on HAART Kaplan-Meier survival estimates appear to stabilise and treatment appears to be most effective after nine months on treatment (Figure 11). *Coetzee et al's* (2004) finding that HAART reduced mortality is consistent with findings from Weidle *et al's* (2002) Ugandan based study.

CD4 counts and chances of survival appear to be positively correlated. None of the patients in *Coetzee et al's* (2004) study died as a direct result of HAART; most patients

died before they could derive the optimal clinical benefit of antiretroviral treatment. Surviving the initial months of treatment appears to be critical for continued survival.

Transitions

Any respondent who reported a perception of poor health at any time after initiating HAART was considered at risk of making a transition to a perception of improved or better health during the observation period. Similarly, any respondent who reported a perception of good health at any time after initiating HAART was considered at risk of making a transition to a perception of poorer health during the observation period.

Table 6: *Perceptions of health, by visit*

	Visit 1		Visit 2		Visit 3	
Do not feel sick	118	45.7%	132	67.7%	86	82.7%
Feel a little sick	67	26%	42	21.5%	18	17.3%
Feel very sick	73	28.3%	21	10.8%	0	0%
Total	258	100	195	100%	104	100%

After approximately six months on HAART, the number of respondents reporting that they are ‘not feeling sick’ increased¹⁶ (Table 6). As discussed below, patients experience the most dramatic improvements in their clinical health during the first three months after initiating HAART (see Figure 16). We are not able to discern which

¹⁶ As discussed above 65 patients who were lost to follow up (did not have a second visit) were classified as ‘deaths’. We only analyse one transition per patient. As discussed below, most patients would make a transition in their perceived health by their second visit. If a patient is censored (i.e. they have not had a transition) and they have a third visit, we are able to analyse whether they subsequently made a transition.

patients reported that they are 'not feeling sick' at visit 2. Patients who reported that they are 'not feeling sick' at visit 2, may have reported that they felt 'very sick', 'a little sick' or 'not feeling sick' at visit 1. In order to explore changes in individual perception of health, we analyse the transition models below.

Seven transitions were estimated to analyse the impact of HAART on perceptions of health. The first three transitions relate to perceptions of improved health:

Transition 1: From a risk pool of 54 respondents, 42 respondents made the transition from feeling *very sick* to *not feeling sick*

Transition 2: From a risk pool of 85 respondents, 63 respondents made the transition from feeling *a little sick* to *not feeling sick*

Transition 3: From a risk pool of 147¹⁷ respondents, 107 respondents made the transition from feeling *very sick* or *a little sick* to *not feeling sick*

The next four transitions relate to deteriorating perceptions of health:

Transition 4: From a risk pool of 161 respondents, 53 respondents made the transition from *not feeling sick* to feeling *a little sick*

Transition 5: From a risk pool of 153 respondents, 46 respondents made the transition from *not feeling sick* to feeling *very sick*

Transition 6: From a risk pool of 189 respondents, 104 respondents made the transition from *not feeling sick* to feeling *very sick, a little sick or dying*

¹⁷ The number of individuals in the risk pool for transition 3 does not equal the sum of the risk pool in transition 1 and 2, because the risk pool in transition 3 also contains all individuals who could have made the transition from feeling 'a little sick' to 'very sick' or 'very sick' to 'a little sick'. The transition indicator for transition 3 is however restricted to respondents who made the transition from feeling 'a little sick' or 'very sick' to 'not feeling sick'.

Transition 7: From a risk pool of 152 respondents, 18 respondents made the transition from *not feeling sick* to *dying*

Non-parametric Analysis

The Kaplan-Meier estimates in Figure 12 indicate that the risk of having perceptions of improved health is twice as high between three and seven months, than between seven and eighteen months. At seven months almost fifty percent of patients are at risk of making the transition from feeling a little sick or very sick to not feeling sick. By contrast the slope of Figure 13 indicates that the process of making the transition from not feeling sick to feeling very sick, a little sick or dying is much slower. After fifteen months less than twenty-five percent of patients are at risk of making the transition from not feeling sick to feeling very sick, a little sick or dying (Figure 13); while after fifteen months approximately sixty percent of patients have made the transition from feeling a little sick or very sick to not feeling sick. It appears that patients ‘survive’ in having a perception of good health longer than they do in having a perception of poor health. In other words a perception of good health is a more stable perception of health because over time the risk of making a transition away from this perception of health is lower than the risk of making a transition to this perception of health.

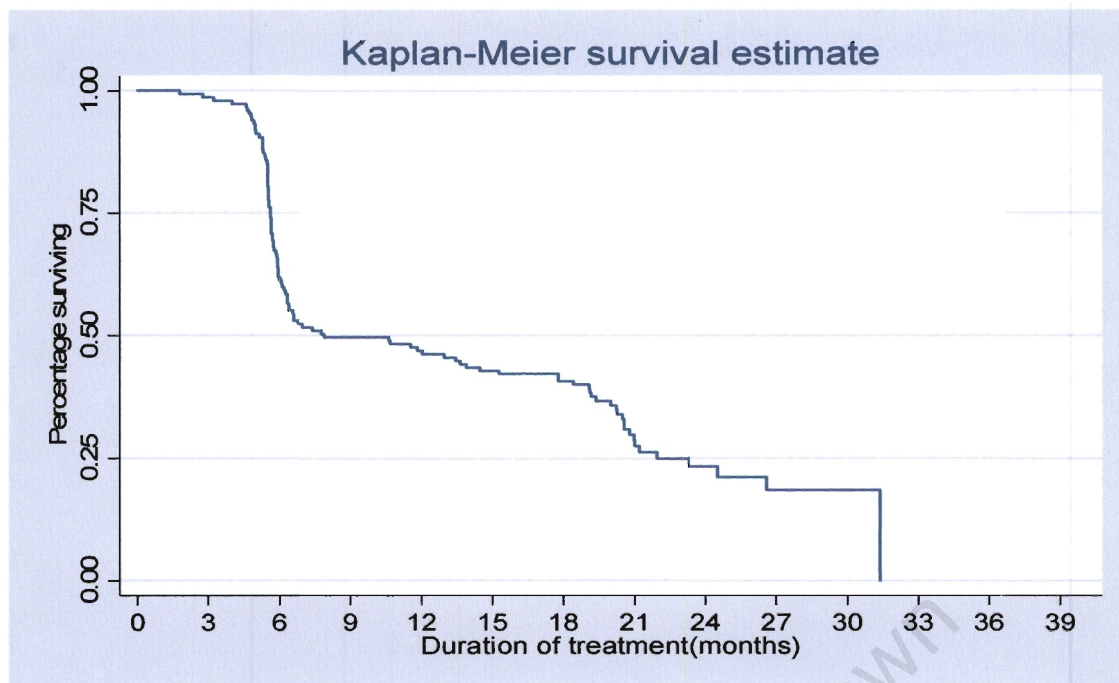


Figure 12: *Kaplan-Meier estimates for transition from feeling very sick or a little sick to not feeling sick*

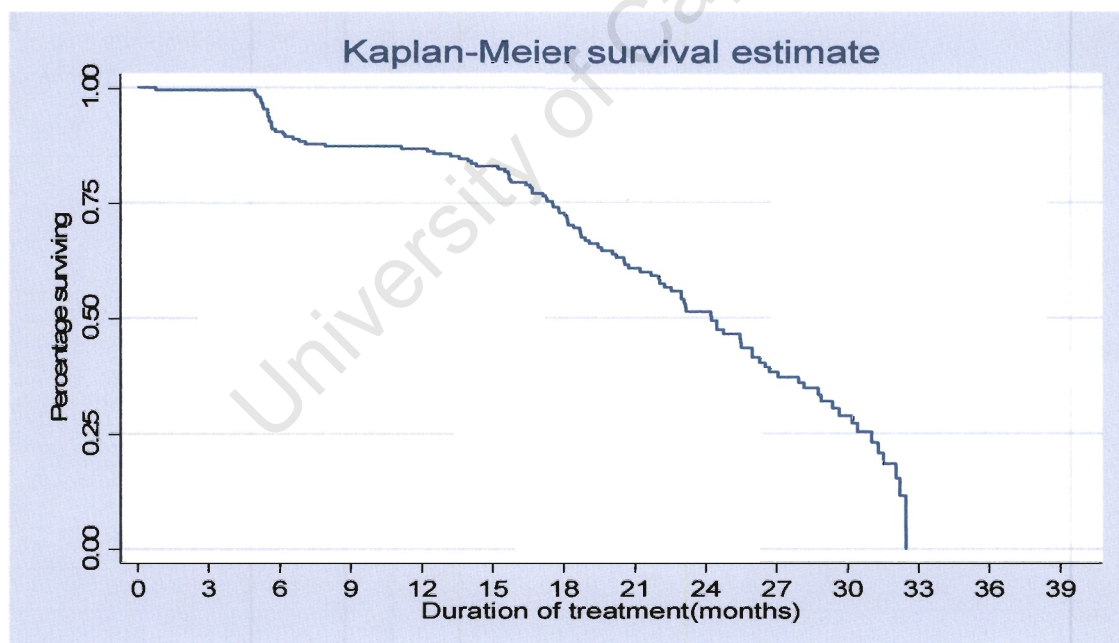


Figure 13: *Kaplan-Meier estimates for transition from not feeling sick to feeling very sick, a little sick or dying*

The Nelson-Aalen hazard estimates for Transition 3 and Transition 6 suggest that gender affects changes in perceptions of health for patients receiving HAART. Figure 15 reveals that over time the hazard of women moving from 'not feeling sick' to feeling 'very sick' or 'a little sick' is greater than the hazard for men. The hazard estimate for the transition from feeling 'very sick or a little sick' to 'not feeling sick' is generally greater for men than for women (Figure 14), while the hazard estimate for the transition from 'not feeling sick' to 'feeling very sick, a little sick or dying', tends to be greater for women than for men (Figure 14). Even though the Nelson-Aalen estimates for men (Figure 14 and Figure 15) indicate that men face greater risks for perceived improved health, the shape of the curves for men and women are not disparate. Nelson-Aalen estimates for men are not increasing sharply while estimates for women are level.

The gender difference in perceptions of health could reflect gender differences in clinical responses to antiretroviral treatment. However, Egger *et al* (2002) studied HIV-positive men and women receiving HAART, all of whom had not had any previous exposure to antiretroviral treatment, and found that there was no gender difference in clinical progression. Similarly, the CASCADE collaboration study (2003) determined that there was no statistically significant difference in risk to AIDS or death for men and women infected through heterosexual intercourse. Even though gender differences in clinical outcomes for patients receiving HAART might not exist, gender differences in perceptions of health can exist.

The shape of the Nelson-Aalen estimates (Figure 14 and Figure 15) suggests that men and women are experiencing similar changes in perceptions of health, but men report these changes sooner than women. A qualitative study by Beck (2004) of Xhosa-

speaking men in Khayelitsha, found that the manner in which masculinity is defined could place pressure on Xhosa men to convey a picture of good health and strength. Illness can be associated with being a failure as a Xhosa man. It is more socially acceptable for Xhosa women to admit to feeling ill than for Xhosa men to admit illness. It appears that Xhosa men in the current study might have felt pressure to convey 'masculine' attitudes towards health, and therefore reported perceptions of improved health sooner than women.

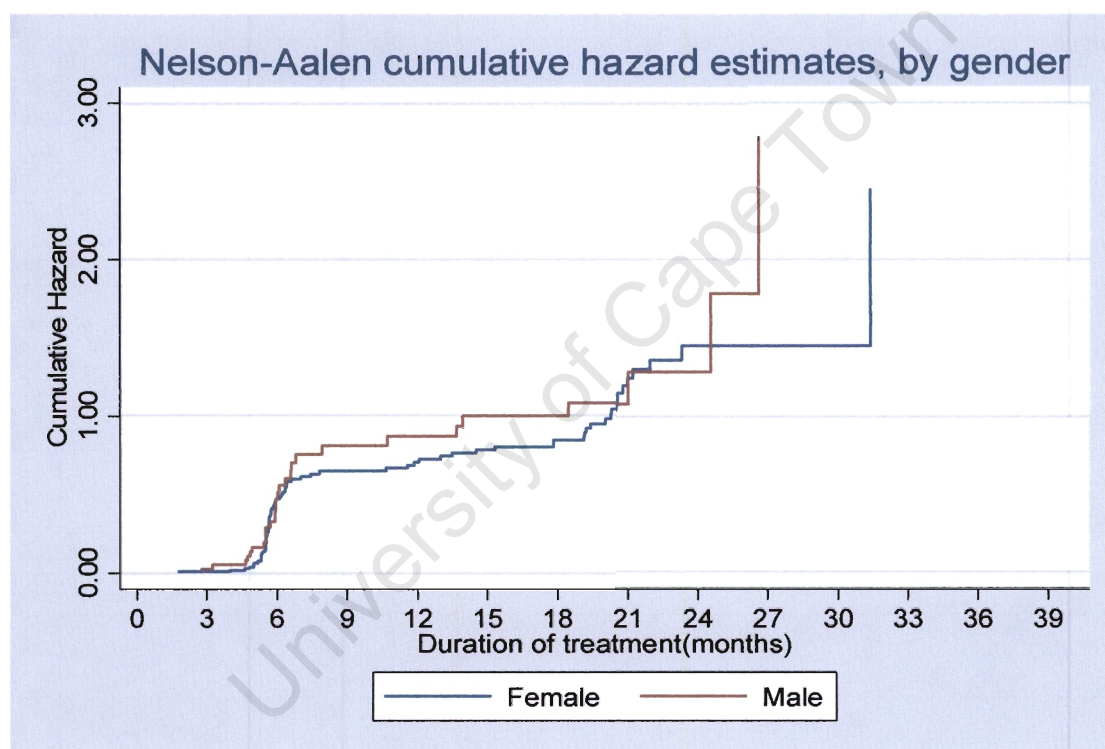


Figure 14: *Nelson-Aalen estimates for transition from feeling very sick or a little sick to not feeling sick*

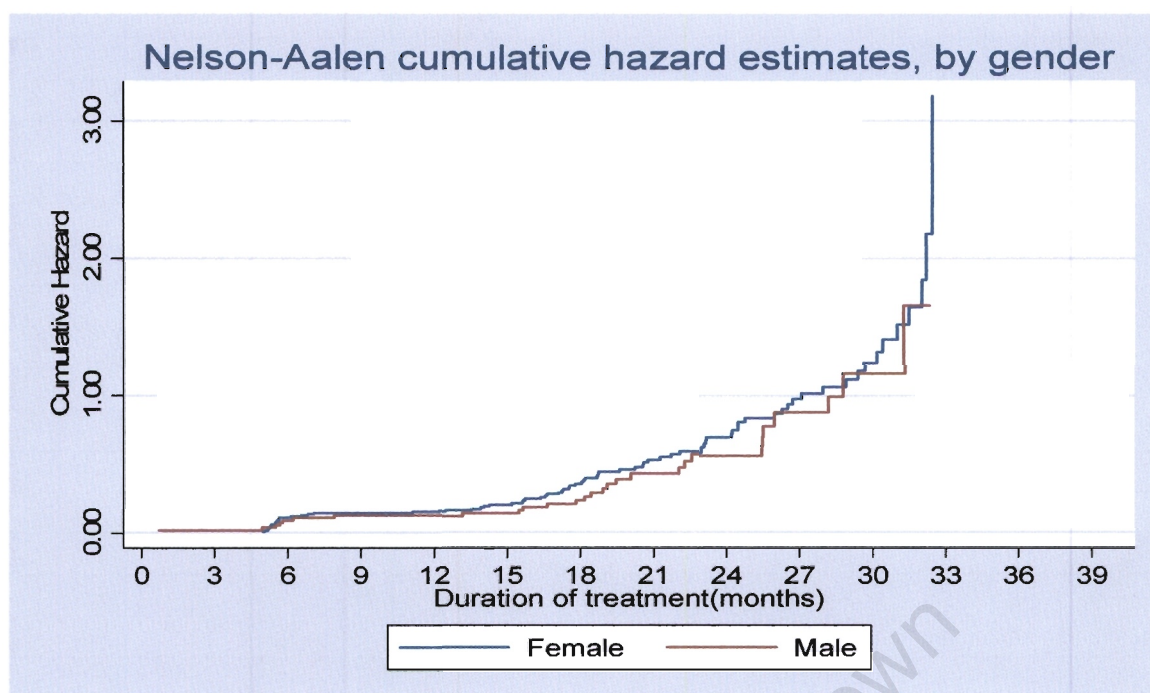


Figure 15: *Nelson-Aalen estimates for transition from not feeling sick to feeling very sick, a little sick or dying*

The results of the nonparametric analysis of perceptions of health are consistent with clinical results from nonparametric analysis in the earlier mentioned adherence study by Coetzee *et al* (2004). The Coetzee *et al* (2004) study analysed the impact of HAART on clinical health. In Coetzee *et al*'s (2004) adherence study the median CD4 count at baseline was 43 CD4 cells/mm³ and 52 percent of patients had a prior AIDS diagnosis. Within the first six months on HAART, CD4 lymphocyte count increased rapidly compared to the pre-treatment level (Figure 16). The most rapid increase in CD4 counts was observed within the first three months of treatment. In subsequent intervals CD4 counts continued to increase, but at slower rates. After twenty-four months on HAART, the median increase in CD4 lymphocyte count compared to baseline was 288×10^6 (95% CI, $181 - 470 \times 10^6$ cells/l), and the median absolute CD4 lymphocyte count at twenty-four months was 323×10^6 cells/l. It is worth noting that the number of AIDS

sick in the Coetzee *et al* (2004) clinical study decreased as a result of HAART, which is consistent with the predictions in the ASSA2003 model (Chapter 1, Figure 7).

A comparison of Figure 12 and Figure 16 suggests that improvements in general perceptions of health mirror to some extent, improved clinical outcomes. The risk of making a transition to perceptions of improved health is greatest between three and seven months of HAART (Figure 12) and CD4 counts increase most rapidly within the first six months of HAART (Figure 16). Improvements in clinical health are antecedent to perceptions of improved health. In the first three months of HAART CD4 counts increase rapidly (indicated by the steepness of the slope in Figure 16). After experiencing rapid improvements in CD4 counts, restoration of clinical health informs perceptions of health, and a significant increase in the risk of making a transition to a perception of improved health is observed after three months (Figure 12).

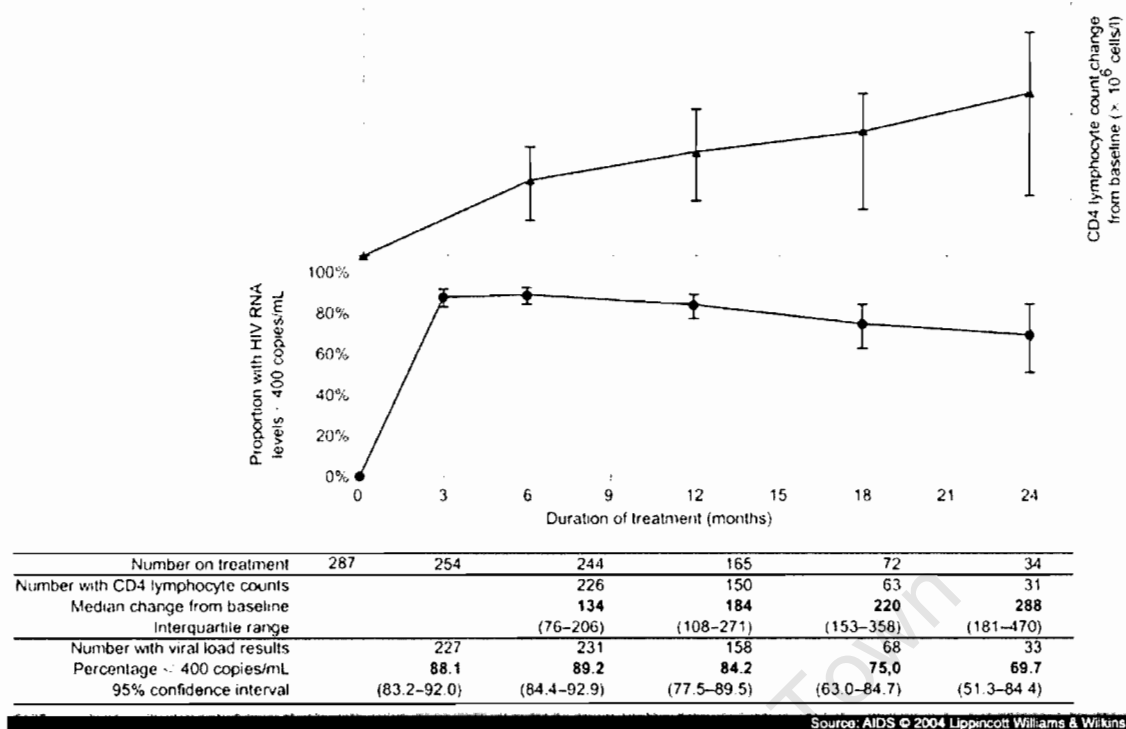


Figure 16: Laboratory outcomes by duration of treatment from Coetzee *et al*'s (2004) adherence study

Perceived improvements in health after starting HAART are consistent with Jelsma *et al*'s (2003) quality of life study using the same MSF patients as this study and the Coetzee *et al* (2004) clinical study. As noted earlier, Jelsma *et al*'s (2003) study used five descriptor health domains - viz. mobility, self-care, usual activities, pain and discomfort, and anxiety and depression - to determine health-related quality of life (HRQOL) for HIV-positive patients enrolled in the MSF HAART programme in Khayelitsha. In Jelsma *et al*'s (2003) study self-perceived HRQOL improved over the course of a year on treatment. This is indicative of a positive relationship between improved clinical outcomes and HRQOL.

The finding that perceptions of health may be positively related to CD4 counts is consistent with findings from the American study by Campsmith, Nakashima and Davidson (2003). They studied self-reported CD4 counts and health-related quality of life dimensions for HIV positive patients (sixty-five percent of whom were receiving HAART) and determined that perceptions of overall health improved as self-reported CD4 counts increased. Patients who recall an increase in their CD4 counts have a more positive perception of their health. In Campsmith, Nakashima and Davidson's (2003) study CD4 counts were reported, but not clinically verified, but this study demonstrates that knowledge of clinical health can influence perceptions of health.

University of Cape Town

Semi-parametric Analysis

Table 7: *Definitions for parameters used in the Cox Proportional Hazard models*

Definition
<i>Demographic</i>
The patient's age when they were diagnosed HIV+
The patient's gender (0= Female, 1= Male)
The patient's marital status (0= Not married, 1= Married)
Level of education (0= None and primary, 1=secondary and tertiary)
<i>Economic</i>
The number of household members that are employed
Whether the patient receives a disability grant (0 = No, 1 = Yes)
Household income
<i>Household</i>
The number of children aged 6 or younger in the household
The number of children aged 7-14 in the household
Whether the patient lives in a shack (0 = No, 1 = Yes)
<i>Health</i>
The number of days that has passed since the patient was diagnosed HIV+
The length of time that a patient received HAART before their first interview

Table 7 lists the covariates used in Transition 1 to Transition 7. The covariates have been grouped according to the demographic, economic, health and household characteristics of the patient. The reason for their inclusion as explanatory variables is provided below.

The age at which an individual, who consequently initiates HAART, is diagnosed HIV-positive is likely to affect his or her perception of health. Egger *et al* (2002) found that for a sample of HIV-positive men and women receiving HAART, all of whom had not had any previous exposure to antiretroviral treatment, the cumulative risk of progression to AIDS or death was greater for patients who were 50 years old or older. Tumbarello *et al* (2004) found higher frequencies of AIDS at HIV diagnosis, lower CD4 cell count and higher mortality in older patients. Greater morbidity and mortality among older patients could be attributed to the more aggressive impact of HIV infection in older populations. It is hypothesised that HIV could be an additional aggravating factor to an already debilitated host potentially presenting numerous comorbidities, less physiological reserves and a less responsive immune system. Older patients in the Tumbarello *et al* (2004) study more frequently had non HIV-related comorbid conditions such as cardiovascular disease, gastrointestinal disorders and diabetes, than a younger matched control group (the control group was matched by sex, year of HIV diagnosis, presence of AIDS defining conditions and type of HAART regimen). There were no statistical differences between viral load reduction and the rapidity, intensity and persistence in increases in CD4 counts for older patients, in comparison to the younger control group receiving HAART. HAART allows older patients to achieve the same viro-immunological response and improvements in health as younger patients. However, older patients present with more severe HIV infection

when they are diagnosed HIV-positive and they are more likely to die because of non HIV-related comorbid conditions.

As noted above, gender could affect perceptions of health for patients receiving HAART.

Patients who are married might feel that they face a lower risk of contracting HIV. Married patients may therefore be tested and diagnosed HIV-positive at much later stages in their HIV disease. If patients who are diagnosed HIV-positive and initiate HAART very late have poorer clinical health outcomes, then married patients might have poorer clinical health outcomes, and therefore perceive that their health is poor.

Levels of education may be linked to literacy. Patients with more than a primary school level of education may be better able to access and understand literature on HAART and its effects on health. They may be able to read to find answers to questions they may not wish to talk to anyone about. Patients who are illiterate and do not wish to speak to anyone about questions they have, might feel more uncertain about their clinical health and thus perceive that their health is poor.

Having an AIDS related 'disability' qualifies individuals to be recipients of a means tested R740 (maximum) disability grant. The disability grant is a significant source of income for patients in this study, with almost 50% of household income derived from the respondent's disability grant. Patients receiving a disability grant might have better health outcomes if the grant is used in health promoting ways – such as on food. Alternatively, patients receiving HAART and experiencing improvements in health may no longer be eligible to receive disability grants. This might force patients to

choose between their health and much needed disability income. The result could be that patients 'yo-yo' between HAART and disability grants (Nattrass, 2004b). Being the recipient of a disability grant thus might encourage respondents to have poorer health in order to secure access to their disability grant.

Having children may affect adherence to HAART in a negative or a positive way (Wood, Tobias and McCree, 2004). Parents may fear for the welfare of their children if they were to die and therefore feel the need to achieve and maintain improvements in health in order to care for their children. Alternatively, the stresses of parenting and the emotional toll that it can place on respondents, could lead some patients to choose to discontinue HAART, which will result in poorer health outcomes. Patient's perception of health may also differ according to the age of the children. Young pre-school aged children (assuming the absence of child care support), will most likely be the caregiver's responsibility for almost every minute of the day. The physical and emotional demands of caring for a young child might place a strain on the patient's already fragile health, and lead to perceived poorer health. School-aged children might place less of a strain on the patient's health, since for a few hours out of every day the child is in another's care. Two separate parameters for having a child in the household were estimated in order to analyse whether the age of the child influences perceptions of health.

A Canadian study by Wood *et al* (2002) found that socio-economic status (determined by linking the patient's postal code to census data on the median income of individuals living in those neighbourhoods) was not significant in explaining survival for patients receiving HAART. However, this study was conducted in an advanced capitalist

country and the research methodology for measuring socio-economic status was somewhat blunt. It is possible that socio-economic status is relevant in a developing country context like the Khayelitsha study.

Socio-economic status can be measured in many ways. The current study uses the type of dwelling (shack or formal), the number of employed members in the household and household income as measures of socio-economic status. The impact that socio-economic status would have on perceptions of health is unclear. Socio-economic status if defined in terms of measures of poverty may, independent of HIV, be associated with greater mortality because poverty is linked to lack of access to health care, malnutrition and parasitic infections (Stillwaggon, 2002; Whiteside, 2002; Nattrass, 2004a). Patients with a poorer socio-economic status might be more susceptible to acquiring highly infectious opportunistic infections such as tuberculosis because of crowded living conditions, and thus experience poorer clinical health outcomes, which could feed into perceptions of poorer health. Alternatively, patients with a poorer socio-economic status – might be more likely to present with opportunistic infections at first clinical consultation because of their susceptibility to these infections – and these patients might have experienced the most dramatic improvements in their health compared to patients from better off socio-economic backgrounds.

Early diagnosis of HIV and subsequent initiation of HAART can lead to better clinical health outcomes (Valdiserri, Holtgrave, and West, 1999). However, in a population of patients who generally were unable to access HAART prior to the MSF establishing clinics in Khayelitsha, it is unclear whether the length of time between HIV diagnosis and initiation of HAART would affect health outcomes. Whether patients were

diagnosed HIV positive early or later, they would generally have been unable to access HAART in the absence of the MSF programme. In the current study the average number of years between an HIV positive diagnosis and initiation of HAART is two years with a standard deviation of a year and eight months. Patients who have fewer days between diagnosis and initiation and HAART may not have better health outcomes than those who were diagnosed years before initiation of HAART, because the MSF selection criteria preferred the most ill patients. Regardless of when patients were diagnosed HIV positive, all patients in the MSF programme were either symptomatic or had CD4⁺T cell counts of less than 50/mm³. Patients who were diagnosed years prior to starting HAART would have defined themselves as terminally ill for longer and this might influence their perceptions of their health.

Most of the patients in the sample (83.5 percent) started HAART on the day that they had their first interview for the socio-economic study. There were, however, some patients who had their first interview after they had started treatment. 'Date' and 'Months on ART' in Appendix A was used to assess whether the date of the patient's first visit, and the number of months that he or she had been on HAART coincided. Patients, for whom the date of their first interview, and the number of months that they reported being on HAART, did not coincide, were included in the models with a parameter for the length of time that they received HAART before their first interview. Perceived improvements in health might diminish over time, such that side effects related to HAART become more salient to informing the patient's perception of his or her health. Patients, who have been on HAART for a longer length of time before their first interview, might well perceive that their health is poorer than patients who were first interviewed at the time that they initiated HAART.

Table 8: Unconditional Mean Differences at baseline, selected characteristics, for patients living in shacks, and patients not living in shacks

	Age	Gender	Years of education	Total household income	Age at HIV+ Diagnosis	Days since HIV+ Diagnosis	Monthly personal income	Number of employed Household members	Have a disability grant
Patients not living in shacks (n=106)									
Mean	34.10	0.26	8.03	R1,384	31.43	810.97	R856	1.20	0.67
Standard deviation	7.25	0.44	4.44	R1,277	7.50	838.64	R937	1.01	0.47
Patients living in shacks (n=154)									
Mean	35.03	0.32	9.06	R1,309	32.27	810.55	R854	0.62	0.77
Standard deviation	7.15	0.47	4.64	R1,067	7.46	628.90	R792	0.68	0.42
Mean differences between those living in shacks and those who are not									
Difference	0.93	0.05	1.03**	-R74	0.83	-0.43	-2.20	-0.57***	0.10*
t-statistic	1.02	0.94	1.79	-0.51	0.88	-0.01	-0.02	-5.50	1.72
p-value	0.31	0.35	0.07	0.61	0.38	0.99	0.98	0.00	0.087

* indicates significance at the 10% level and ** at the 5% level *** at the 1% level

Table 9: Unconditional Mean Differences at baseline, for selected characteristics of patients attending various clinics

	Age	Gender	Years of education	Total household income	Age at HIV+ Diagnosis	Days since HIV+ Diagnosis	Monthly personal income	Number of employed Household members
Michael M (n=179)								
Mean	34.71	0.33	8.49	R1,361	31.31	738.04	R884	0.89
Standard deviation	8.20	0.47	4.37	R1,198	8.44	511.35	R903	0.96
Nolungile (n=198)								
Mean	34.68	0.29	8.82	R1,573	31.76	811.49	R909	0.80
Standard deviation	6.94	0.45	4.76	R1,229	7.06	681.18	R861	0.76
Site B (n=192)								
Mean	34.47	0.27	8.55	R1,115	31.63	870.01	R791	0.87
Standard deviation	6.53	0.45	4.63	R1,001	6.97	894.75	R804	0.90
Mean differences between clinics								
Prob>F	0.97	0.63	0.12	0.03	0.82	0.48	0.62	0.76
F-statistic	0.03	0.46	0.88	3.56	0.20	0.74	0.47	0.27

Table 8 reports the unconditional means, at baseline (visit 1), for selected variables for patients living in shacks, and patients not living in shacks. Table 8 indicates that at

baseline, patients living in shacks are statistically significantly more likely to receive a disability grant than patients living in formal housing.

Patients living in shacks on average have an extra year of education (9.1) than patients not living in shacks i.e. formal housing (8.0). Interestingly there are no significant differences in average monthly personal income and household income between patients living in shacks versus those not living in shacks. There was, however, a significant difference between the average number of employed household members for shack dwellers (0.6) and those in formal housing (1.2). The number of employed household members might be the most important factor that affects the type of dwelling in which the average respondent lives. The influence may be through a non-income manner. The number of employed members in the household might affect the likelihood of accessing a home loan. Individuals with more employed members in the household might find it easier to prove that they will not default on repaying their home loan, since there are other members in the household earning more 'stable' income from employment.

Table 9 indicates that at baseline, the average household income of patients attending Site B clinic is significantly lower than patients attending the other clinics. Stratification by clinic controls for any other unobserved heterogeneity between the various clinic attendees. Stratification of the models by clinic also stratifies by household income.

Models

We now turn to an analysis of the seven possible transitions as described earlier.

Transition 1: The transition from feeling *very sick* to *not feeling sick*

Transition 2: The transition from feeling *a little sick* to *not feeling sick*

Transition 3: The transition from feeling *very sick* or *a little sick* to *not feeling sick*

Transition 4: The transition from *not feeling sick* to feeling *a little sick*

Transition 5: The transition from *not feeling sick* to feeling *very sick*

Transition 6: The transition from *not feeling sick* to feeling *very sick, a little sick or dying*

Transition 7: The transition from *not feeling sick* to *dying*

The first three transitions look at the transition from perceived ill health to perceived improved health. The next four transitions relate to the transition from perceived good health to perceived ill health. Each transition will be analysed in turn using Cox Proportional Hazard Models.

Transition 1: *Transition from feeling very sick to not feeling sick (Table 10)*

The following transition looks at the characteristics that patients possess, which impacts their risk of making the transition from feeling ‘very sick’ to ‘not feeling sick’.

Table 10: Results from Cox Proportional Hazard models for individuals who made the transition from feeling very sick to not feeling sick

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	0.95 (0.04)	0.204
The patient's gender (1=Male)	3.16 (1.75)	0.038**
The patient's marital status	0.97 (0.46)	0.952
The patient's level of education	1.02 (0.45)	0.964
The number of household members that are employed	1.54 (0.31)	0.030**
Whether the patient receives a disability grant	0.67 (0.40)	0.489
Household income	1.00 (0.00)	0.887
The number of children aged 6 or younger in the household	0.42 (0.13)	0.005***
The number of children aged 7-14 in the household	0.65 (0.18)	0.116
Whether the patient lives in a shack	4.58 (2.62)	0.008***
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.095*
The length of time that a patient received HAART before their first interview	0.90 (0.05)	0.073*
Number of observations	62	
Number of subjects	54	
Number of failures	42	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

The results of the transition analysis for those who moved from feeling ‘very sick’ to ‘not feeling sick’ are reported in Table 10. The results show that having a child under six years old in the household severely reduces the risk of a person moving from feeling ‘very sick’ to ‘not feeling sick’. The risk of a patient with a child younger than six years old in the household making the transition from ‘very sick’ to ‘not feeling sick’, was 42 percent the risk of patients without any young children in their household making this transition. Patients without young children in their households might have a greater risk of having better perceived health, because they are not burdened with the emotional and physical stress of caring for a very young child. This result could reflect the added physical, mental and emotional strain that having a young child can place on HIV positive patients receiving HAART. As mentioned in Chapter 1, HAART can introduce stress related to: the need to maintain a high level of adherence to medication regimens; having to attempt to manage the adverse side effects that may result from HAART, and of tolerating the uncertainty regarding how long one will continue to benefit from HAART.

Patients who live in shacks are 4.58 times more likely to make a transition from feeling ‘very sick’ to ‘not feeling sick’. This may seem like a counterintuitive result, but it may be linked to patients from poorer socio-economic backgrounds presenting for HAART when they were very ill. Patients, who initiate HAART when they are very ill, might view their recovery as more ‘miraculous’ than other patients. This might explain why patients living in shacks have a greater risk of making the transition to perceived improved health.

Every additional employed member in the household increases the patient's risk of making the transition from feeling 'very sick' to 'not feeling sick' by 154 percent. In South Africa access to employment is a key determinant of poverty (Leibbrandt *et al*, 2000) and the unemployed are twice as likely to be poor as opposed to the employed (Seekings, 2003). If poverty and health are positively correlated, it is likely that patients from poorer households were extremely ill when initiating HAART, and dramatic improvements in their clinical health possibly had a much greater impact on their perceptions of their health. However, it is important to note that the positive effect of the number of employed household members holds in a model in which total household income is being controlled for. There is, in other words, something about the employment status of these members that matters (beyond its proxying for household income) for perceived improved health. Perhaps the sense of security that comes with having more people in employment helps generate a more positive outlook amongst HAART patients about improvements in their health status.

Males face a 3.16 times greater risk of experiencing a transition from feeling very sick to not feeling sick. This could reflect machismo and men's desire to be viewed as healthy, strong and virile. Hence, the duration of spells of feeling 'very sick' is shorter for men than for women.

Patients who have had a longer interval between the time they initiated HAART and their first interview, are less likely to experience a transition from feeling 'very sick' to 'not feeling sick'. This is consistent with the pattern in Figure 16, where patients experience dramatic improvements in their clinical health within the first few months after initiating HAART (CD4 counts increase rapidly), but after some time on treatment

the increase in CD4 counts plateau. Initial dramatic improvements in clinical health might cause patients to have very positive perceptions of their health. However, after some time they might become accustomed to their improved health, and their perceptions of their health might become more sensitive to side effects related to treatment.

Every day that passes between the patient being diagnosed HIV positive and the patient initiating HAART, decreases the patient's risk of making a transition from feeling 'very sick' to 'not feeling' sick by 1 percent. From this finding it can be extrapolated that if a week passes between diagnosis and initiating HAART, the respondent's risk of making a transition from feeling very sick to not feeling sick decreases by 7 percent. Initiating HAART as soon as possible after an HIV positive diagnosis appears to dramatically improve patients' perception of their health.

Transition 2: *Transition from feeling a little sick to not feeling sick (Table 11)*

The next transition we will explore is transitions from feeling 'a little sick' to 'not feeling sick'. As shown in Table 11, when controlling for all parameters, there are no significant parameters in explaining this transition.

Table 11: Results from Cox Proportional Hazard models for individuals who made the transition from feeling a little sick to not feeling sick

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	0.99 (0.02)	0.616
The patient's gender	0.94 (0.36)	0.868
The patient's marital status	0.73 (0.27)	0.390
The patient's level of education	1.21 (0.54)	0.674
The number of household members that are employed	0.87 (0.18)	0.500
Whether the patient receives a disability grant	0.72 (0.30)	0.391
Household income	0.99 (0.00)	0.403
The number of children aged 6 or younger in the household	1.26 (0.28)	0.300
The number of children aged 7-14 in the household	1.05 (0.20)	0.791
Whether the patient lives in a shack	1.62 (0.58)	0.176
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.590
The length of time that a patient received HAART before their first interview	1.00 (0.00)	0.231
Number of observations	100	
Number of subjects	85	
Number of failures	63	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

Transition 3: *Transition from feeling very sick or a little sick to not feeling sick*
(Table 12)

We now consider the transition from feeling sick (whether very sick or just a little sick) to not feeling sick.

Table 12: *Results from Cox Proportional Hazard models for individuals who made the transition from feeling very sick or a little sick to not feeling sick*

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	0.97 (0.02)	0.145
The patient's gender	1.18 (0.31)	0.515
The patient's marital status	0.84 (0.20)	0.472
The patient's level of education	1.00 (0.26)	0.995
The number of household members that are employed	1.02 (0.12)	0.870
Whether the patient receives a disability grant	0.95 (0.26)	0.849
Household income	1.00 (0.00)	0.988
The number of children aged 6 or younger in the household	0.91 (0.14)	0.518
The number of children aged 7-14 in the household	0.79 (0.11)	0.082**
Whether the patient lives in a shack	1.43 (0.35)	0.148
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.722
The length of time that a patient received HAART before their first interview	1.00 (0.00)	0.567
Number of observations	198	
Number of subjects	147	
Number of failures	107	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

From Table 12 it is apparent that patients, who live in household's that contain a child aged 7-14 as a household member, have a risk of making the transition from feeling 'very sick' or 'a little sick' to 'not feeling sick' that is 79 percent the risk of patients without a child aged 7-14 in the household. This might once again reflect the emotional and physical distress that can be linked to having young children in the household that need to be cared for.

Transition 4: *Transition from not feeling sick to feeling a little sick (Table 13)*

The following transition looks at the characteristics that patients possess, which impacts their risk of making the transition from 'not feeling sick' to feeling 'a little sick'.

Table 13: Results from Cox Proportional Hazard models for individuals who made the transition from not feeling sick to feeling a little sick

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	0.96 (0.02)	0.132
The patient's gender	0.95 (0.38)	0.902
The patient's marital status	0.74 (0.28)	0.442
The patient's level of education	0.65 (0.29)	0.328
The number of household members that are employed	1.23 (0.24)	0.290
Whether the patient receives a disability grant	0.52 (0.19)	0.081*
Household income	0.99 (0.00)	0.011**
The number of children aged 6 or younger in the household	1.32 (0.29)	0.204
The number of children aged 7-14 in the household	1.30 (0.24)	0.159
Whether the patient lives in a shack	3.15 (1.14)	0.001***
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.805
The length of time that a patient received HAART before their first interview	1.00 (0.00)	0.673
Number of observations	276	
Number of subjects	161	
Number of failures	53	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

Table 13 shows that HAART patients who live in shacks are 3.12 times more likely to make the transition from ‘not feeling sick’ to feeling ‘a little sick’. This may be the result of patients living in informal housing (which is less likely to have indoor plumbing, electricity, and possibly has poorer insulation from elements such as wind and rain) being more susceptible to illnesses that make them feel ‘a little sick’.

HAART patients who live in households with a high household income, have a risk of making the transition from ‘not feeling sick’ to feeling ‘a little sick’ that is 0.99 times the risk of patients residing in households with less income. In other words every additional Rand of household income decreases the patient’s risk of making the transition from ‘not feeling sick’ to feeling ‘a little sick’ by 1 percent.

Respondents who do not receive a disability grant are more likely to make the transition from ‘not feeling sick’ to feeling ‘a little sick’, even when controlling for household income. Patients who receive a disability grant have most likely been ‘disabled’ by their HIV disease in the past or are HIV-positive people who have been weakened by a previously existing disability. Since initiating HAART and experiencing dramatic improvements in health, their attitudes towards their health remain positive for longer. Patients with a disability grant are therefore more likely to remain in the pool of patients who perceive that they do not feel ‘very sick’.

Transition 5: Transition from not feeling sick to feeling very sick (Table 14)

The next model (Table 14) explores the transition from feeling ‘a little sick’ to ‘not feeling sick’.

Table 14: Results from Cox Proportional Hazard models for individuals who made the transition from not feeling sick to feeling very sick

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	1.00 (0.02)	0.934
The patient's gender	1.66 (0.69)	0.222
The patient's marital status	0.81 (0.33)	0.595
The patient's level of education	1.29 (0.71)	0.639
The number of household members that are employed	1.16 (0.28)	0.545
Whether the patient receives a disability grant	0.92 (0.43)	0.853
Household income	0.99 (0.00)	0.216
The number of children aged 6 or younger in the household	0.66 (0.21)	0.194
The number of children aged 7-14 in the household	1.26 (0.23)	0.194
Whether the patient lives in a shack	1.93 (0.75)	0.092*
The number of days that has passed since the patient was diagnosed HIV+	1.00 (0.00)	0.219
The length of time that a patient received HAART before their first interview	1.01 (0.00)	0.001***
Number of observations	272	
Number of subjects	153	
Number of failures	46	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

As shown in Table 14, the length of time, which the respondent has been on HAART prior to their first interview, is very significant in explaining a patient's risk of making the transition from 'not feeling sick' to feeling 'very sick'. Patients, who were on treatment for longer before their first interview, are more likely to make the transition from 'not feeling sick' to feeling 'very sick'. This could be indicative of initial improvements in health becoming less salient, and HAART related side effects becoming more salient, in informing perceptions of health, the longer the patient has been on treatment.

Patients who live in shacks are 1.93 times more likely to make the transition from 'not feeling sick' to feeling 'very sick'. Again this result could reflect patients living in informal housing (which is less likely to have indoor plumbing, electricity, and possibly poorer insulation from elements such as wind and rain) being more susceptible to illnesses, even after HAART has helped reconstitute their immune systems.

Transition 6: *Transition from not feeling sick to feeling a little sick or very sick or dying (Table 15)*

We now consider the transition from 'not feeling sick' to feeling 'a little sick' or 'very sick' or 'dying'.

Table 15: Results from Cox Proportional Hazard models for individuals who made the transition from not feeling sick to feeling a little sick or very sick or dying

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	0.99 (0.01)	0.842
The patient's gender	1.10 (0.30)	0.731
The patient's marital status	0.86 (0.22)	0.575
The patient's level of education	0.92 (0.30)	0.811
The number of household members that are employed	1.12 (0.16)	0.426
Whether the patient receives a disability grant	0.80 (0.21)	0.396
Household income	0.99 (0.00)	0.027**
The number of children aged 6 or younger in the household	1.02 (0.17)	0.900
The number of children aged 7-14 in the household	1.19 (0.14)	0.132
Whether the patient lives in a shack	1.90 (0.48)	0.010**
The number of days that has passed since the patient was diagnosed HIV+	1.00 (0.00)	0.398
The length of time that a patient received HAART before their first interview	1.00 (0.00)	0.023**
Number of observations	329	
Number of subjects	189	
Number of failures	104	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

The model in Table 15 above combines Transition 4 and Transition 5 and indicates that patients from poorer socio-economic status (lower household income or living in a shack), or who have a longer elapsed period between initiating HAART and their first interview, are less likely to experience improved health on HAART. They are more likely to make the transition from ‘not feeling sick’ to feeling ‘a little sick’ or ‘very sick’ or ‘dying’.

Transition 7: *Transition from not feeling sick to dying* (Table 16)

The following transition looks at the characteristics that patients possess, which impacts their risk of making the transition from ‘not feeling sick’ to ‘dying’.

Table 16: Results from Cox Proportional Hazard models for individuals who made the transition from not feeling sick to dying

Parameters	Hazard and Standard Error	P-Value
The patient's age when they were diagnosed HIV+	1.07 (0.04)	0.037**
The patient's gender	1.00 (0.73)	0.999
The patient's marital status	1.12 (0.79)	0.875
The patient's level of education	0.61 (0.42)	0.477
The number of household members that are employed	1.44 (0.76)	0.489
Whether the patient receives a disability grant	0.56 (0.43)	0.456
Household income	0.99 (0.00)	0.760
The number of children aged 6 or younger in the household	1.01 (0.56)	0.981
The number of children aged 7-14 in the household	0.89 (0.33)	0.747
Whether the patient lives in a shack	1.94 (1.47)	0.381
The number of days that has passed since the patient was diagnosed HIV+	1.00 (0.00)	0.108
The length of time that a patient received HAART before their first interview	1.01 (0.00)	0.00***
Number of observations	245	
Number of subjects	152	
Number of failures	18	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level *** at the 1% level*

Dying indicates that patient was lost to follow up. As argued earlier the vast majority of these ‘deaths’ are in fact likely actual deaths. The results of the transition analysis for those who moved from ‘not feeling sick’ to ‘dying’ are reported in Table 16. The results show that patients with a greater number of days between initiating HAART and their first interview have a greater risk of making the transition from the risk pool of patients who perceive that they do not feel sick to dying. Patients, who have been on HAART for a longer period of time and have experienced improvements in their health, might be more likely to take a ‘treatment holiday’ and take a break from using HAART when they feel better, in order to get relief from treatment related side effects. This may affect their chances of survival.

Patients, who are older when diagnosed HIV-positive, are 1.07 times more likely to make the transition from the risk pool of patients who perceive that they do not feel sick, to dying. This might reflect that fact that older patients, who experience improvements in their clinical health, have a greater risk of dying regardless of their HIV-disease.

Discussion

Patients who: do not have children younger than age six living in their households; are male; have more employed members in the household; had a longer interval between the time they initiated HAART and their first interview; and initiated HAART soon after being diagnosed HIV positive, have a greater risk of making the transition from feeling very sick to not feeling sick. Patients who are HIV-positive might feel the pressure to dispel stigma surrounding HIV/AIDS and portray only positive images of

themselves, which could leave no room for them to acknowledge periods when they are not feeling well (Soskolne, 2003). Males in this sample are less willing to remain in the pool of patients who feel very ill, indicative perhaps of their desire to portray their idea of masculinity, which is to be healthy and virile. Patients should perhaps be counselled to place less pressure on themselves to portray a healthy, virile image, because it may not allow them the space to acknowledge being ill if they suffer from treatment related side effects in the future. Patients with young children in the household should be encouraged to seek counselling in order to help them cope with the strain of living with a chronic disease and being a caregiver.

The length of time that a patient has been on HAART prior to his or her first interview, and the patient's age when diagnosed HIV-positive, increases the patient's risk of making the transition to dying. The greater risk of older patients dying most likely reflects the prevalence of comorbidities among older patients. The debilitation of health, related to old age, most likely affects the risk of these patients making the transition to death.

Patients' who live in households with less income, who do not have a disability grant, who have had more time pass between initiating HAART and their first interview, and who live in shacks, have a greater risk of making the transition from not feeling sick to perceived poorer health (Transition 4 and Transition 6). Patients in formal dwellings, on average, do not have greater household incomes than patients living in shacks (Table 8). However, patients who live in shacks might simply be more susceptible to contracting illnesses, because of living in the type of dwelling in which they live. One might hypothesise that characteristics unique to living in a shack such as; poor

insulation against cold and wet conditions, and cramped living space might, even in the absence of HIV disease, affect shack dwellers' susceptibility to contracting illness.

Conclusion

The demographic, economic, health and household characteristics of patients influence their perceptions of their health. In general, patterns in perceptions of health appear to follow clinical health patterns. As the clinical health of patients in the MSF sample improved, so too did their perceived health.

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The impact of HAART on Labour Supply

Introduction

As discussed in Chapter 1 in the absence of antiretroviral treatment, the progression of HIV disease reduces workers' productive capacity, increases absenteeism, and eventually forces workers to give up their jobs. Prior to the advent of antiretroviral treatment, deteriorating health was a salient consideration in the labour supply decisions of people living with HIV/AIDS. In the HAART era health has once again become as salient consideration, but this time it is restored health that influences the labour supply decisions of HIV-positive people.

The findings in Chapter 2 suggest that, in the sample of patients receiving HAART through the MSF programme in Khayelitsha, perceptions of improved health mirror improvements in clinical health. HIV-positive patients, who abstained from supplying labour because of ill health, might be encouraged to re-enter the labour market as a result of HAART's perceived effectiveness in reducing morbidity and mortality. The current chapter explores this final part of the research hypothesis. More concretely, it analyses the linkage between personal perceptions of improved health and labour supply decisions.

As in Goldman and Boa's (2004) study, the current study expects that in general HAART will be effective in helping working patients remain employed. HAART-related improvements in perceived health most likely play a greater role in labour supply transitions among the unemployed and non-labour force participants than among the employed. It is likely that workers, who were ill and remained in employment, would not make health-related transitions out of employment when their health improves. For this reason, individuals who were unemployed or out of the labour market when starting HAART are the focus of the current labour supply analysis. More, specifically, this chapter investigates whether perceptions of improved health translated into HIV-positive individuals making the transition from being unemployed or non-labour market participants, to supplying or wanting to supply labour to the labour market.

This chapter is arranged in the following manner: the first section explains the models used in the analysis; the second section contains a discussion of the findings of the model; the third section highlights the policy implications of the findings in the study; and the final section contains the conclusion.

Transitions

Semi-parametric analysis using Cox proportional hazard regression was utilised to study transitions in labour supply. The Cox models in the current analysis use the Breslow method for handling ties. One-way transitions were analysed for univariate and multivariate models. The Cox models were once again stratified by clinic to account for unobserved heterogeneity. Stratification by clinic was deemed necessary

because the underlying hypothesis of the study is that perceptions of health affect labour supply decisions. If the clinic that an individual attends affects his or her perception of health, and perceptions of health influence labour supply, then stratification by clinic is necessary in order to ensure that the effects of the covariates are measured correctly.

Any respondent who was classified as unemployed (broad) or a non-labour force participant (broad) at any time after initiating HAART was considered at risk of making a transition to another labour market category. Four models were estimated to analyse the impact of HAART on labour supply. Models that analyse the transitions from broadly classified as unemployed are:

Transition 8: From a risk pool of 83 respondents, 60 respondents made the transition from *unemployed* to *employed*

Transition 9: From a risk pool of 61 respondents, 27 respondents made the transition from *unemployed* to *non-labour force participant*

Models that analyse the transitions from broadly classified as non-labour force participants are:

Transition 10: From a risk pool of 58 respondents, 40 respondents made the transition from *non-labour force participant* to *employed*

Transition 11: From a risk pool of 64 respondents, 44 respondents made the transition from *non-labour force participant* to *unemployed*

Transition 8 and Transition 9 were estimated in order to answer the question: “Do unemployed individuals who make the transition to being a non-labour force participant possess characteristics that differentiate them from unemployed individuals who are able to find employment?”

Transition 10 and Transition 11 were estimated in order to answer the question: “Are non-labour force participants who find a demand for the labour that they are willing to supply merely lucky, or do they possess characteristics that differentiate them from non-labour force participants who are unable to find employment?”

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Table 17: *Definitions for parameters used in the Cox Proportional Hazard models*

Demographic

The patient's age when they were diagnosed HIV+

The patient's gender (0= Female, 1= Male)

The patient's marital status (0= Not married, 1= Married)

Level of education (0= None and primary, 1=secondary and tertiary)

Economic

The patient stopped working for HIV-related reasons

The number of household members that are employed

Whether the patient receives a disability grant (0 = No, 1 = Yes)

Household income

Household

The number of children aged 6 or younger in the household

The number of children aged 7-14 in the household

Whether the patient lives in a shack (0 = No, 1 = Yes)

Health

Public disclosure of HIV+ status

The number of days that has passed since the patient was diagnosed HIV+

The length of time that a patient received HAART before their first interview

Whether the patient has made the transition from feeling a little sick or very sick to not feeling sick (0 = the patient has not made a transition, 1 = the patient has made a transition)

The classic labour supply model has individuals choosing between hours spent in work and hours spent in leisure. The current analysis makes use of the concept of 'constructed identity', (i.e. how an individual defines himself or herself), as a means of probing the motivating factors that influence HIV-positive individuals' allotment of hours to either work or leisure. Individuals assume many roles which all form an integral part of their constructed identity. Most HIV-positive patients receiving HAART have to reconcile two important roles. The first role that a HIV-positive person may assume is created when he or she experiences the major negative life event of being diagnosed HIV-positive. As discussed in Chapter 1, an HIV-positive diagnosis requires redefining oneself as a person living with a chronic, and in the absence of antiretroviral treatment, debilitating and terminal disease. Since the individual will always be infected with the virus, even if they receive HAART, they will always be able to assume the role of 'a person with a chronic illness' (Nixon and Renwick, 2003).

The second dominant role, which most individuals feel pressure to assume, is the role of a productive member of society. For any working aged individual, societal pressure most likely forces one to define fulfilment of the role of a productive member of society, by assuming the role of 'a worker'. There are negative connotations attached to not being employed. A working-aged individual who devotes all his or her time to leisure might be considered lazy, lacking in ambition, or even a burden to the household that needs to support him or her. As patients receiving HAART experience improvements in their clinical health, they would most likely feel pressured, both by themselves and others, to assume 'a worker' role (Nixon and Renwick, 2003). Various factors can influence which role a person living with HIV/AIDS chooses to assume.

As discussed in Chapter 1, almost all patients who start HAART will experience nausea, vomiting and diarrhoea early in treatment but these side effects are usually transient. Other HAART-related side effects such as bone-marrow suppression, lipodystrophy syndrome (peripheral fat loss and central fat accumulation), fatigue, headaches, nightmares, insomnia, impaired concentration and drug hypersensitivity that can manifest themselves in skin rashes with or without a fever; may interfere with the individual's ability to supply labour. HIV disease or HAART-related side effects might 'debilitate' HIV-positive individuals with regards to supplying certain types of labour.

Judge Edwin Cameron's (2005) experience with HAART highlights the reality of side effects' intrusion on his daily routine. For two hours after taking his medication, which he takes twice a day, he has diarrhoea. One could imagine that for a construction worker on site, a seamstress in a factory, a secretary, or almost any individual who has no control over the scheduled time that they have to supply their labour, making frequent trips to the bathroom would affect their productivity. Fatigue, symptoms of pain and anxiety about taking HAART and its long-term effectiveness could also negatively impact worker productivity.

The role of 'a person with a chronic illness', living with HIV-disease and treatment related side effects, may provide some social legitimacy to working-aged HIV-positive individuals abstaining from supplying labour. However, as stated earlier, the societal and personal value attached to the role of 'a worker', places pressure on working aged HIV-positive individuals to supply labour. They may also worry about being stigmatised because they are not contributing productively to their households or society (Maughan-Brown, 2004).

If an individual chooses to assume exclusively the role of 'a person with a chronic illness', he or she would choose to devote all their time to leisure and not supply any labour. If an individual chooses to assume the role of 'a worker', he or she would divide his or her time between supplying labour and leisure. These two roles can be regarded as both mutually exclusive and conflicting, or they can be reconciled and assumed successfully, as Judge Edwin Cameron and others have done. Whether or not an individual is able to reconcile these two roles would most likely depend on the characteristics that the individual is endowed with, as discussed below.

The patient's age at diagnosis would most likely affect his or her ability to reconcile the two roles discussed above. If age is positively correlated with number of years spent in the labour market, then individuals receiving HAART who are older when they are diagnosed HIV-positive might have spent more time in the labour market than individuals who are younger at diagnosis. If attachment to the labour market diminishes with time spent in the labour market - such that someone who has been working for thirty years would be more likely to retire than someone who has been working for three years - then individuals receiving HAART who are older when they are diagnosed HIV-positive might find it easier to abandon the role of 'a worker', and devote all their time to leisure. For patients receiving HAART, who were older at diagnosis, improvements in clinical health might not remove legitimacy for their decision to assume the role of 'a person with a chronic illness' exclusively.

Gender and marital status may collectively and independently influence HAART patients' labour supply decisions. Being employed and able to provide for one's family is an important part of Xhosa men's definition of masculinity (Beck, 2004). This

suggests that the dominant role desired by men would most likely be the role of ‘a worker’. The progression of HIV disease emasculates Xhosa men when it destroys their ability to be productive in the labour market. HAART-related improvements in health restore their ability to once again be active in the labour market.

As discussed in Chapter 1, women can have their ability to be caregivers and homemakers eroded as they experience the progression of HIV disease. Women, who feel improvements in their health, and restoration of their ability to once again assume the role of caregiver and homemaker, might choose to abstain from the labour market and exclusively assume the role of ‘a person with a chronic illness’.

Married women might feel more discouraged from supplying labour and seeking the role of ‘a worker’ than married men, and they might be more likely to allow their husbands to assume the role of the breadwinner. Single women, who might not have a partner to provide for them financially, might be more inclined to assume the role of ‘a worker’ and make transitions to supplying labour in order to support themselves and their dependants.

The patient’s level of education might influence his or her perception of labour demand, and consequently influence labour supply decisions. If an individual with a primary level of education is convinced that there is very little or no demand for the labour that they are able to supply, or they believe that they will be paid very little for the labour that they are able to supply, they might feel legitimated in a decision to assume exclusively the role of ‘a person with a chronic illness’, and devote all of their time to leisure. Even if these patients experience improvements in their health, they

might remain discouraged, by a perceived lack of demand for labour, and not wish to supply labour.

Intuitively, if deteriorating health was the dominant factor that influenced a patient's decision to leave the labour market, improvements in health will most likely be the dominant factor that influences his or her decision to return to the labour market. Patients who stopped working because of their HIV-disease might be more likely to make the transition to supplying or wanting to supply labour. Patients with a past history of employment at least know that there has been a demand for their services in the past. This may encourage them to return to the labour market. Furthermore, they may have obtained skills and experience, which give them an advantage over those who have never worked, when it comes to obtaining work in the future. Additionally, there is evidence that a lot of recruitment of workers in South Africa is done through networks (Seekings, 2003). Individuals who stopped working because of HIV-related reasons might have stronger networks in the labour market, through previous work experience and employers and colleagues, and the existence and utilisation of these networks might translate into a greater likelihood of making the transition to the role of 'a worker' when their health improves.

Patients, who live in households that have more employed household members, might have broader networks - through these employed household members themselves, their colleagues and/or their employer - in the labour market than individuals with fewer or no other employed household members. Patients in households with more employed household members might therefore be encouraged to assume the role of 'a worker' and search for and perhaps even obtain employment through utilising these household-

related networks. Furthermore, if every other working aged member of the household is employed, and the patient is not, they might feel 'peer pressure' to also find employment. Alternatively, patients in households with many employed household members might feel that the other 'healthier' household members who have employment should provide for them, and thus choose to abstain from supplying labour, and feel justified in exclusively assuming the role of 'a person with a chronic illness'.

The Canadian study by Lem *et al* (2005) of HIV-positive patients looked at transitions out of unemployment after a year of receiving HAART. All the patients in Lem *et al*'s (2005) study were unemployed at baseline and receiving HAART consisting of at least three drugs. Lem *et al*'s (2005) multivariate analysis determined that patients, who augmented their monthly income with government assistance in the form of a disability grant, were significantly more likely to remain unemployed after a year of HAART than those without disability grants. This finding is supported by Dray-Spira *et al*'s (2003) study of HIV-positive individuals in two regions in France (more than eighty percent of this sample received antiretroviral treatment), and Brook *et al*'s (2004) study of HIV-positive individuals in Los Angeles (sixty-two percent of whom had been exposed to antiretroviral treatment), that found that being a recipient of a disability grant acted as a perceived barrier to plans to re (enter) the labour market. Patients who receive a disability grant might be discouraged from assuming the role of 'a worker' to prevent jeopardising their state provided disability grants, which as discussed in Chapter 2 is an important source of income for patients in the MSF sample. They may, of course, also be less able to enter the labour market than those without disability grants.

There are costs associated with actively searching for employment (i.e. phone calls, sending faxes, travelling to interviews, purchasing newspapers), and patients who earn an income, or are able to access income from other household members, might have a greater likelihood of being able to finance these search costs. Lem *et al's* (2005) univariate analysis concluded that HIV-positive patients receiving HAART who earned higher incomes were significantly more likely to gain employment. Patients in the MSF sample who are part of households with higher incomes might be more willing to assume the role of 'a worker' when they experience improvements in their health, given that they are able to finance costs related to job search. Alternatively, patients in households with more income might feel that the household does not need them to generate income through supplying labour. They may instead decide to take care of the household, in order to allow other household members the opportunity to engage in employment, and assume exclusively the role of 'a person with a chronic illness'.

Research on women's employment, for women in general populations, has established that having pre-school aged children to care for significantly depresses women's labour participation (Dex *et al*, 1998). The current study analyses whether the labour participation patterns of HIV-positive individuals receiving HAART, who have pre-school aged (less than age six) children in their households are consistent with such findings. Someone in the household has to stay home to care for any pre-school aged children in the household. Given that most of the respondents in the MSF sample are women, and all the respondents can assume exclusively the role of 'a person with a chronic illness' and abstain from supplying labour, many patients in the MSF sample might decide to assume exclusively the role of caregiver to young children.

As children grow older, their mother's chances of seeking employment will increase (Dex *et al*, 1998). Having school-aged (age seven to fourteen) children in a household might encourage patients in the MSF sample to supply labour because these children will have many school related expenses. Patients residing in households that contain school going children, will most likely share the burden of household income being siphoned by expenditure on schooling for these children. Patients in the MSF sample might wish to assume the role of 'a worker' in order to supplement household income that gets diverted to school related expenses.

As discussed in Chapter 2 (Table 8), patients who live in shacks have significantly fewer other members in the household who are employed, and are significantly more likely to have disability grants. As discussed earlier in this chapter, both of these factors (living in a shack or having a disability grant) might discourage patients from supplying labour, even when they experience improvements in their clinical health. Alternatively, given that shack-dwellers live in households with fewer wage-income generating individuals, these patients might feel more pressure to assume the role of 'a worker'. In Ezzy's (1999) study of HIV-positive patients in Australia (seventy-six percent of whom received two or more antiretroviral medications), poverty and economic hardships were dominant factors that influenced labour supply decisions. Patients living in shacks might feel more social and personal pressure to supply labour, in order to mitigate potential individual and household economic hardship, as a result of having fewer wage-income generating individuals in the household and living in an informal dwelling.

As noted in Chapter 1, one of the selection requirements of the HAART programme was disclosure of HIV status. Patients need only have disclosed their status to one other individual in order to fulfil this requirement. Some patients in the MSF sample chose to disclose their status to only one other individual, which they most likely did in order to meet the requirement for treatment (Coetzee and Nattrass, 2004). Lack of disclosure might be indicative of fear of stigma. There were nine categories of individuals in the survey to whom patients could have disclosed their HIV+ status viz. health professionals, support group, partner, family member(s), friend(s), spiritual leader, current or former employer, public and other. In the current analysis a patient was assumed to have made a public disclosure of their HIV+ status if they disclosed their HIV status to three or more such categories. Fear of discrimination in the workplace is a concern for many individuals living with HIV/AIDS, regardless of their access to HAART (Brashers *et al*, 1999; Dray-Spira *et al*, 2003; Ferrier and Lavis, 2003; Nixon and Renwick, 2003; Brooks *et al*, 2004; Cameron, 2005). Patients in the MSF sample who have made a more public disclosure of their HIV status might be less concerned about workplace stigma, and so be more likely to supply labour. Alternatively, individuals who have publicly disclosed their HIV status might have suffered more discrimination. Experiences of discrimination might make them wary of potential discrimination in the workplace, given that they have publicly disclosed their status. Public knowledge of their status might act as a barrier to them deciding to supply labour.

As discussed in Chapter 2, early diagnosis of HIV and subsequent initiation of HAART can lead to improved perceived health. Transition 1 (Chapter 2) determined that, patients who have a greater number of days between being diagnosed HIV-positive and

initiating HAART, have a significantly lower risk of making the transition from perceiving that they were very sick, to perceiving that they were not sick. Patients, who felt that they were very ill for a longer period of time, might be more wary of improvements in their health, and be more likely to assume exclusively the role of 'a person with a chronic illness'.

The length of time that a patient received HAART before their first interview is significant in Transition 1 and Transition 6 (Chapter 2). Patients, who have a longer length of time between initiating HAART and their first interview, have a lower risk of making a transition to improved perceived health. For patients who have been receiving HAART for a longer period of time, time on treatment might allow the initial positive improvements in health to be offset by negative impressions of health, as a result of treatment-related side effects. Experiencing treatment-related side effects can affect physical functioning and cause wariness related to the sustainability of improvements in health and discourage patients from wanting to assume the role of 'a worker' (Brasher, 1999; Nixon and Renwick, 2003; Lem *et al*, 2005).

Patients who made the transition to improved perceived health in Transition 1, Transition 1 or Transition 3, might be more likely to make transitions in their labour supply decisions. If health and perceptions of health directly inform labour supply decisions; then these patients might be more likely to assume or want to assume the role of 'a worker'.

Models

We now turn to an analysis of the four possible labour supply transitions as described earlier.

The models that analyse transitions from broadly classified as unemployed are:

Transition 8: Transition from *unemployed* to *employed*

Transition 9: Transition from *unemployed* to *non-labour force participant*

The models that analyse transitions from broadly classified as non-labour force participants are:

Transition 10: The transition from *non-labour force participant* to *employed*

Transition 11: The transition from *non-labour force participant* to *unemployed*

Transition 8: Transition from unemployed to employed (Table 18)

The next transition will explore patients making the transitions from being unemployed to finding employed, as shown in Table 18.

Table 18: Results from Cox Proportional Hazard models for individuals who made the transition from unemployed to employed

Parameters	Hazard and Standard Error	P-value
The patient's age when they were diagnosed HIV+	0.97 (0.02)	0.193
The patient's gender	1.00 (0.37)	1.000
The patient's marital status	1.11 (0.42)	0.790
The patient's level of education	1.58 (0.63)	0.253
The patient stopped working for HIV-related reasons	2.71 (0.93)	0.004***
The number of household members that are employed	1.44 (0.36)	0.147
Whether the patient receives a disability grant	1.97 (0.97)	0.165
Household income	0.99 (0.00)	0.908
The number of children aged 6 or younger in the household	0.98 (0.20)	0.924
The number of children aged 7-14 in the household	1.13 (0.21)	0.520
Whether the patient lives in a shack	1.06 (0.39)	0.867
Public disclosure of HIV+ status	0.99 (0.55)	0.987
The number of days that has passed since the patient was diagnosed HIV+	1.00 (0.00)	0.858
The length of time that a patient received HAART before their first interview	0.99 (0.00)	0.779
Whether the patient has made the transition from feeling a little sick or very sick to not feeling sick	1.00 (0.43)	0.994
Number of observations	1558	
Number of subjects	83	
Number of failures	60	

The standard error is reported in brackets

* indicates significance at the 10% level and ** at the 5% level. *** at the 1% level

Table 18 indicates that when controlling for all other parameters, whether a patient stopped working because of HIV related reasons is the only significant parameter in explaining the transition from being unemployed to being employed. This parameter is strongly significant, patients who stopped working because of HIV related reasons, are 2.71 times more likely to make the transition from unemployed to employed. If the reason that the respondent stopped working was because they chose to discontinue work because of their deteriorating health, and not because they were retrenched or fired, it is likely that he or she might be able to return to their old job when his or her health improves. Unfortunately the survey did not ask sufficient detailed questions for us to test this hypothesis. Since these individuals credit health as the reason that they were excluded from the employed labour force, it is likely that once they start experiencing improvements in their health, they would be keener to return to employment. Prior work experience most likely makes these individuals more employable, and acts as an enabling factor that allows them to find a demand for the labour that they are willing to supply.

In the univariate analysis, which isolates a single parameters effect on risk of transition from unemployed to employed, there were no significant parameters other than whether or not the individual had stopped working for HIV-related reasons. It is notable that regardless of any other characteristics that an individual might possess, the only parameter that increases his or her risk of finding a demand for the labour that he or she is willing to supply, is whether or not the individual has work experience and was forced out of the labour market by illness. Having ties to the labour market, through previous employment, appears to be key in facilitating the recovered patient's re-entry into the workforce. Note that whether a patient made the transition from feeling a little

sick or very sick, to not feeling sick, had no statistically significant impact on the risk of making the transition from unemployed to employed.

Transition 9: *Transition from unemployed to non-labour force participants (Table 19)*

The next transition will explore patients making the transition from being unemployed to no longer wishing to find employment, as shown in Table 19.

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Table 19: Results from Cox Proportional Hazard models for individuals who made the transition from unemployed to non-labour force participants

Parameters	Hazard and Standard Error	P-value
The patient's age when they were diagnosed HIV+	0.98 (0.04)	0.706
The patient's gender	0.52 (0.35)	0.340
The patient's marital status	0.53 (0.33)	0.316
The patient's level of education	1.00 (0.57)	0.988
The patient stopped working for HIV-related reasons	2.06 (1.18)	0.207
The number of household members that are employed	0.86 (0.29)	0.659
Whether the patient receives a disability grant	0.20 (0.19)	0.085*
Household income	1.00 (0.00)	0.019**
The number of children aged 6 or younger in the household	0.62 (0.36)	0.418
The number of children aged 7-14 in the household	0.66 (0.23)	0.222
Whether the patient lives in a shack	1.11 (0.77)	0.885
Public disclosure of HIV+ status	1.30 (1.14)	0.768
The number of days that has passed since the patient was diagnosed HIV+	1.00 (0.00)	0.012**
The length of time that a patient received HAART before their first interview	0.99 (0.00)	0.788
Whether the patient has made the transition from feeling a little sick or very sick to not feeling sick	1.52 (1.02)	0.531
Number of observations	1135	
Number of subjects	61	
Number of failures	27	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level. *** at the 1% level*

Individuals living in households with a relatively high household income have a greater risk of making the transition from being unemployed to being a non-labour force participant (Table 19). This result would be consistent with respondents living in relatively 'richer' households feeling less pressure to earn income from employment, as there are other members in the household that are able to generate income through employment or grants. These patients instead decide to assume exclusively the role of 'a person with a chronic illness'. This result would also be consistent with respondents who live in relatively 'poorer' households continuing to want employment in order to assist with income-related hardships (i.e. lack of expenditure for food, clothing, shelter etc.) that such poorer households are vulnerable to experiencing.

Respondents with more days between diagnosis and initiation of HAART have a greater risk of making the transition from being unemployed to being a non-labour force participant. As discussed in Chapter 2, patients who have a greater number of days between being diagnosed HIV-positive and initiating HAART, have a significantly higher risk of remaining in the risk pool of perceiving that they were very ill. Given that these patients perceive that they are very ill for a longer period of time, they might be warier of improvements in their health, and consequently have a greater risk of making the transition to assuming exclusively the role of 'a person with a chronic illness'.

Being a disability grant recipient weakly explains, in relation to the other significant parameters, having a lower risk of making the transition from wanting to work to choosing to refrain from being a part of the labour market. This finding is contrary to the studies mentioned earlier, which found that patients who were disability grant

recipients were less likely to want to work. All the previous studies were conducted in developed countries. The current study is set in a developing country context, with low-income individuals. The finding that disability grant recipients have a greater risk of remaining in the pool of individuals who want to find employment, could reflect the fact that they want to work because they can afford to finance their job searches. Individuals who are not recipients of disability grants might not be able to afford the costs associated with job search (viz. cost of telephone calls, cost of purchasing a newspaper). Not being able to afford the costs associated with job search might discourage individuals from wanting to work.

Transition 10: *Transition from non-labour force participant to employed (Table 20)*

The following transition looks at the characteristics that patients possess, which impacts their risk of making the transition from non-labour force participant to employed.

Table 20: Results from Cox Proportional Hazard models for individuals who made the transition from non-labour force participant to employed

Parameters	Hazard and Standard Error	P-value
The patient's age when they were diagnosed HIV+	0.93 (0.03)	0.030 **
The patient's gender	0.79 (0.40)	0.641
The patient's marital status	0.69 (0.42)	0.543
The patient's level of education	1.51 (0.79)	0.431
The patient stopped working for HIV-related reasons	1.82 (0.76)	0.150
The number of household members that are employed	1.34 (0.38)	0.295
Whether the patient receives a disability grant	0.68 (0.53)	0.620
Household income	1.00 (0.00)	0.246
The number of children aged 6 or younger in the household	0.23 (0.12)	0.006 ***
The number of children aged 7-14 in the household	0.59 (0.18)	0.078 *
Whether the patient lives in a shack	1.56 (0.82)	0.401
Public disclosure of HIV+ status	0.19 (0.13)	0.018 **
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.205
The length of time that a patient received HAART before their first interview	0.99 (0.02)	0.726
Whether the patient has made the transition from feeling a little sick or very sick to not feeling sick	0.83 (0.56)	0.780
Number of observations	1064	
Number of subjects	58	
Number of failures	40	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level. *** at the 1% level*

Individuals who have pre-school aged children in their household have a greater risk of remaining in the pool of potential workers who choose to refrain from wanting to enter the labour market. Every additional pre-school aged child in a household lowers the patient's risk of making the transition from being a non-labour force participant to being employed by 23 percent (Table 20). This suggests that patients, who do not live in households with very young children to care for, appear to be able to find a demand for their labour, even if they initially did not want to work.

Individuals who have made a more public disclosure of their HIV status have a lower risk of making the transition from being a non-labour force participant to being employed. It is unclear why this is the case. It could be that these individuals might have experienced discrimination when they publicly disclosed their HIV status, and that these negative experiences might have put them off wanting to enter the workforce.

Individuals who were diagnosed as HIV-positive when they were older have a lower risk of making the transition from being a non-labour force participant to being employed. This might be indicative of the fact that individuals who are older when diagnosed HIV-positive being more likely to remain retired from the labour market. Or it could be indicative of individuals who are older when they were diagnosed HIV-positive being less likely to find a demand for the labour that they are willing to supply.

Individuals who have school aged children in their household have a greater risk of remaining in the pool of non-labour force participants, but it is less significant than other significant parameters. Patients who do not want to work, and who live in households with young children to care for, have a lower risk of supplying labour if it is

demanded. This could reflect recovered patients accepting the responsibility of exclusively caring for young children in the household.

Note that the variable ‘whether a patient has made the transition from feeling a little sick or very sick to not feeling sick’ had no statistically significant impact on the risk of making the transition from non labour-force participant to employed.

Transition 11: *Transition from non-labour force participant to unemployed (Table 21)*

The final transition looks at the characteristics that patients possess, which impacts their risk of making the transition from non-labour force participant to unemployed.

Table 21: Results from Cox Proportional Hazard models for individuals who made the transition from non-labour force participant to unemployed

Parameters	Hazard and Standard Error	P-value
The patient's age when they were diagnosed HIV+	0.96 (0.03)	0.228
The patient's gender	2.33 (1.37)	0.148
The patient's marital status	0.83 (0.49)	0.752
The patient's level of education	3.34 (1.57)	0.010 **
The patient stopped working for HIV-related reasons	3.90 (1.70)	0.002 ***
The number of household members that are employed	1.72 (0.51)	0.066 *
Whether the patient receives a disability grant	1.98 (1.28)	0.295
Household income	0.99 (0.00)	0.620
The number of children aged 6 or younger in the household	1.17 (0.39)	0.625
The number of children aged 7-14 in the household	0.73 (0.21)	0.274
Whether the patient lives in a shack	1.27 (0.61)	0.617
Public disclosure of HIV+ status	0.85 (0.54)	0.796
The number of days that has passed since the patient was diagnosed HIV+	0.99 (0.00)	0.052 *
The length of time that a patient received HAART before their first interview	1.00 (0.02)	0.879
Whether the patient has made the transition from feeling a little sick or very sick to not feeling sick	0.18 (0.17)	0.073 *
Number of observations	1188	
Number of subjects	64	
Number of failures	44	

The standard error is reported in brackets

** indicates significance at the 10% level and ** at the 5% level. *** at the 1% level*

When controlling for all other parameters, patients who stopped working because of HIV related reasons are 3.90 times more likely to make the transition from being a non-labour force participant, to wanting to be employed and seeking work (Table 21). If the reason that the respondent stopped working and chose to abstain from supplying labour was because deteriorating health forced them to discontinue work, then improvements in health are likely to persuade them to desire to work again.

Patients with a secondary or tertiary level of education are 3.34 times more likely to make the transition from being a non-labour force participant to wanting to be employed. Patients with higher levels of education might perceive that demand for educated labour exists and is rewarded. This might explain their significantly greater risk of making the transition from choosing to abstain from the labour market to wanting employment.

Patients who have had more days pass between their diagnosis and initiation of HAART have a lower risk of making the transition from a non-labour force participant to unemployed. This is consistent with the result in Transition 9 (Table 19), which found that patients who have had more days pass between their diagnosis and initiation of HAART are more likely to remain in the pool of non-labour force participants.

Having other household members who are linked to the labour market increases the risk of individuals who are non-labour force participants making the transition to wanting to be employed. Every additional employed member in the household increases the patient's risk of transition from non-labour force participant to broadly defined unemployed by 1.72 times. Patients who live in households comprised of more

employed household members, might feel ‘peer pressure’ to make the transition to employment.

After controlling for all other parameters, patients who have made the transition to perceiving that they were not sick, are less likely to make the transition from non-labour force participant to unemployed. The finding that perceptions of improved health increases a patients risk of remaining in the pool of non-labour force participants might seem counter-intuitive. However, it speaks to the complexities related to making the transition to wanting to re (enter) the labour market. All the patients who made the transition to having better perceived health had previously felt that they were ill. These patients might be just as cautious about the sustainability of improvements in their health as patients in the risk pool of individuals who continued to feel that they were ill. Patients who have perceived improvements in their health may even have a stronger inclination to preserve their health improvements, as opposed to patients who remain in the risk pool. Thus, even though some patients perceive that they feel better after time spent on HAART, they might still feel that their health is too fragile to re (enter) the labour market.

Discussion

Assuming the role of ‘a worker’ or exclusively assuming the role of ‘a person with a chronic illness’ is a complex decision. Patients who have a greater risk of finding a demand for the labour they are willing to supply, and consequently make the transition from either unemployed (Transition 8) or non-labour force participant (Transition 10) to employed, have specific characteristics that increase their risk of finding a demand

for the labour they are willing to supply. After controlling for all other individual characteristics and perceptions of improved health; patients who have prior work experience and stopped working because of HIV-related reasons (Table 18); patients in households who do not have children aged fourteen or less who need to be cared for (Table 20); patients who have not publicly disclosed their HIV status (Table 20); and patients who were younger when they were diagnosed HIV-positive (Table 20); have a greater risk of making the transition to finding, and accepting, a demand for their labour.

Even though perceptions of improved health are not significant in explaining transitions to employment, it does not mean that improved health is not important in enabling patients to make this transition. In the absence of HAART-related health improvements, patients in the sample would have been debilitated or dead, and consequently have been out of the labour market. The findings in the analysis highlight HIV-positive individuals' characteristics that affect their likelihood of searching for employment and being in employment. Improvements in health are not as significant in explaining transitions to employment as; whether or not the patient possesses characteristics that will increase the probability of finding a demand for their labour (i.e. has work experience, or is young); or possesses characteristics that will increase the probability of being a non-labour force participant (i.e. have young children to care for, or public disclosure of HIV status).

Patients who have a greater risk of making the transition to wanting to assume the role of 'a worker' (Transition 11), or have a greater risk of remaining in the pool of individuals wanting to work and not becoming discouraged (Transition 9), are endowed

with specific characteristics. After controlling for all other individual characteristics; patients who stopped working because of HIV related reasons (Table 21); have a secondary or tertiary level of education (Table 21); have fewer days between their HIV-positive diagnosis and initiation of HAART (Table 19, Table 21); have other household members who are employed (Table 21); have not made the transition from feeling that they were sick to feeling that they are not sick (Table 21); come from lower income households (Table 19); or are disability grant recipients (Table 19); have a greater risk of making the transition to being unemployed, or remaining in a risk pool of individuals who are unemployed.

Patients who are able to finance job search through their disability grant, who have attachments to the labour market through other household members, who want to increase their household's income, who have prior work experience and discontinued employment because of the progressions of their HIV disease, who feel that their level of education makes them marketable, who started HAART soon after being diagnosed HIV-positive, and who remain in the risk pool of feeling ill; have a greater risk of not choosing to be a non-labour force participant. Having access to seeking employment, and perceptions of marketability, appears to be important factors that prevent individuals from becoming non-labour force participants.

Policy Implications

The Operational Plan for comprehensive HIV and Aids Care, Management and Treatment for South Africa (2003) currently defines the best that the AIDS management programme can achieve in the following manner:

“There is currently no cure for AIDS. The best that an AIDS management programme can achieve is to prolong the lives of people living with HIV and AIDS, so that they can remain productive members of society.”

(Department of Health, 2003, p. 20)

The above quote links the success of the programme to not merely prolonging life, but prolonging life in order that individuals living with HIV/AIDS can remain productive members of society. The definition of the term ‘productive members of society’ is not crystallised in the Operational Plan. When is an individual considered a ‘productive member of society’? The term ‘productive member of society’ could refer to a myriad of roles assumed by an individual. A ‘productive member of society’ could refer to someone fulfilling the role of a parent in order to rear the next generation of South Africans. Or the term ‘productive member’ in the Operational Plan might be suggestive of economic concepts of productivity, which would refer to an individual being productive if they assume the role of ‘a worker’.

Defining the term ‘productive member of society’ is important. If the success of the AIDS treatment programme hinges on restoring individuals health in order that they are

able to assume the role of a 'productive member of society', but we do not know what this role should be, then how would we evaluate whether the programme is successful? If being 'a productive member of society' is defined in terms of being a worker, and the aim of the AIDS treatment programme is to prolong life in order to allow people to re (enter) the workforce; and if individuals in the AIDS treatment programme are consequently unable to find employment, then the HAART programme could be deemed unsuccessful.

In the current study, not every working aged individual who has had his or her health restored by HAART was able to make the transition to being a worker. Individuals with prior work experience and stopped working because of HIV-related reasons, who live in households with fewer young children to care for, who have not publicly disclosed their HIV status and possibly been exposed to discrimination, and who were younger when they were diagnosed HIV-positive, have a greater risk of making the transition to employment. The analysis in this study has shown that HAART is successful in improving perceptions of health, and increasing the pool of labour that is able to work and wants to work, but wanting to supply labour is not necessarily accompanied by a demand for this labour. This finding is consistent with the finding in Coetzee and Nattrass (2004), HAART can restore the health of patients living with HIV/AIDS, and thus increase the unemployment rate, but it cannot remove structural barriers to employment. Put simply, HAART creates a labour force, but HAART does not create employment. Demand has to be created for the labour that patients on HAART are able to supply. In the absence of creating demand for the labour of recovered patients, the AIDS programme could fall short of achieving its 'best' outcome.

Given the legacy of access to HAART in South Africa, most individuals accessing HAART through the public sector are likely to be poor and unemployed. As discussed in Chapter 2, income generated from disability grants is an important source of income for households in the MSF sample. As discussed previously, restored health jeopardises an HIV-positive individual's access to a disability grant. The analysis in this study highlights that it would seem unconscionable to provide HAART at the cost of jeopardising an important source of income (the disability grant), without providing them with a demand for their labour so that income generated through employment can compensate for income lost if disability grants are removed.

Removing the disability grant and placing the welfare of HAART patients and their households in jeopardy, while not creating employment, might seem unconscionable, but it is also unjust to give a R740 disability grant to someone who is HIV-positive and has had their health restored, while giving R0 to someone who is unemployed and HIV-negative. At present South Africa has no social security available to the unemployed. Unemployed individuals who have worked before and have contributed to the Unemployment Insurance Fund are entitled to only three months unemployment insurance after becoming unemployed. Giving a R740 disability grant, which is a significant amount of income for poor households, to HIV-positive individuals who have had their health restored, while providing no social security to the unemployed, could possibly create a perverse incentive for the unemployed to contract HIV (Natrass 2004b).

Any suggested policy has to achieve two aims: it has to cushion the shock to household income of the loss of a disability grant; while simultaneously not encouraging the

unemployed to contract HIV in order to gain access to any 'preferential' income provided to recovered HIV-positive individuals. One possible suggestion, as put forward by Nattrass (2004a; Nattrass 2004b), would be to introduce a universal basic income grant. The basic income grant would provide every South African with a minimal monthly stipend. The greater the number of members in a household, the greater the cumulative monthly stipend received from the basic income grant. Since the basic income grant would be universal, there would be less incentive to contract HIV, and it would help cushion the shock to households who lose a disability grant. The manner in which a basic income grant would be financed is contentious (Le Roux, 2002; Samson, 2002b), but what is not contentious is that in the absence of creating demand for South Africa's large pool of unemployed labour, some form of social security is needed to alleviate poverty among the unemployed, both HIV-positive and HIV-negative.

The ideal sustainable solution would be to create a demand for the large pool of potential labour that exists in South Africa. HIV-positive individuals, who have had their health restored by HAART, might still experience diminished physical functioning related to fatigue and symptoms of pain. Many, however, would require a more flexible work schedule in order to allow them days off in order to recuperate if they are feeling ill, or if they need to go to the clinic to collect their medication or have a check-up.

Limitations

A limitation of the study is that it is arguable that the MSF sample is not a representative sample of HIV-positive HAART patients attending public health facilities. The MSF HAART programme was the first of its kind in South Africa. The people who came forward for treatment at the time, may well not be representative of the group of people coming forward for treatment in government clinics today. It is possible that the MSF sample is comprised of a higher proportion of people that are particularly proactive.

Another possible limitation of the study is its use of a subjective measure of health as opposed to using objective health markers such as CD4 counts and viral loads. It is possible that these objective health measures might have produced more significant health results when estimating the labour market transitions (Transition 8 – Transition 11). Lack of access to such data prevented their inclusion in the models.

An additional limitation of any study grounded in econometric modelling is that, at best, it can only demonstrate strong correlation, but never causation. Quantitative research struggles with the ‘Why’ question. Ideally, the interpretation of the results in the models could be supported by qualitative data collected from patients in the MSF sample in order to assess whether results have been interpreted correctly. Interpretations of results put forward in this paper are by no means exhaustive. For every suggested interpretation of a result in this study, there are most likely other opposing and complimentary interpretations.

Despite the limitations of the study, it has some noteworthy findings. The findings highlight issues that are worth further consideration, which can inform discourse around policies related to the public rollout of HAART and employment.

Conclusion

Many people living with HIV/AIDS have experienced significant improvements in their health as a result of Highly Active Antiretroviral Treatment (HAART). South Africa's public sector rollout of HAART has made treatment accessible to a greater number of people living with HIV/AIDS. The research hypothesis of this study was that over time patients on HAART would perceive that their health had improved, and that their perceptions would influence their labour supply decisions. The analysis found that HAART has indeed resulted in patients perceiving that their health had improved. Deciding whether or not to re (enter) the labour market is, however, a complex decision for a HIV-positive individual, and dependent on specific characteristics that they possess. Perceived health is but one of many factors that inform labour supply decisions. Perceptions of improved health is significant in explaining transitions from being a non-labour force participant to being unemployed. When controlling for all other individual characteristics, perceptions of improved health is not significant in explaining transitions to employment. Patients who have worked before, who live in households with fewer young children to care for, who have not publicly disclosed their HIV status, and who were younger when they were diagnosed HIV-positive, have a greater risk of making the transition to employment.

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Appendix A

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

Household Level Economic Effects of HAART

TO THE INTERVIEWER:

Was the questionnaire completed? ☐ Yes ☐ No

If not, please indicate the reason:

- ☐ interviewee refused
- ☐ interviewee missed clinic visit
- ☐ not enough time
- ☐ other reason, specify _____

Time interview started: _____

Time interview finished: _____

Hello. I am _____. I am going to ask you some questions in order to find out how your antiretroviral therapy is affecting your family. All the information that you provide is confidential; it will be seen only by the researchers who are organizing this study. It will not be passed on to your doctor, the clinic staff, the government, or anyone else. Your responses will not affect your access to antiretroviral therapy in any way. You will not be given anything in exchange for your participation in this survey; it is only to help us to understand how antiretroviral therapy affects your household.

It is important that you answer the questions honestly; there are no right or wrong answers. You will not be judged based on your responses. You do not have to answer a particular question if you do not want to. You are also free to stop the interview at any time if you do not want to continue. Your responses are very helpful for helping us better understand the effects of your treatment on your household situation. Do you have any questions before we start?

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

A. Household Background

Gender: _____

Year of birth: _____

Highest grade of school passed: _____

Months on ARV therapy: _____

A.1. What type of dwelling do you live in?

- ☐ Formal dwelling (*e.g. house on a separate site, dwelling in a block of flats, town cluster semi-detached house, and house flat room in backyard*)
- ☐ Informal dwelling (*e.g. shack in backyard, shack in informal settlement*)
- ☐ Room in hostel/compound for workers provided by employer or municipality
- ☐ Other (specify _____)

A.2. How many rooms does your house have?

- ☐ 1
- ☐ 2-3
- ☐ 4 or more

A.3. Does your house have...

yes no

- | | | |
|--------------------------|--------------------------|---------------------|
| ☐ | ☐ | 1. an inside toilet |
| ☐ | ☐ | 2. running water |
| ☐ | ☐ | 3. electricity |
| ☐ | ☐ | 4. a refrigerator |
| ☐ | ☐ | 5. a radio |
| ☐ | ☐ | 6. a telephone |
| ☐ | ☐ | 7. a television |
| ☐ | ☐ | 8. a car |

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

A.4. First I would like to know about who lives in your household and whether or not they work or study. Please list all the people living in your household (not including yourself), their relationship to you, their year of birth, and their gender. "Household" should include all those who live on the same property and sleep at the dwelling at least four nights a week—including babies and non-family members.

Step 1				Step 2: Now think about your [relationship, i.e. mother, sister, etc].			
Code	Relationship to you	Year of birth	Gender F or M	In the last month, what was her/his occupation(s)? <i>Indicate all that apply.</i> 1 Paid work 2 Unpaid work, including housework and voluntary work 3 Unemployed 3 Student / learner 4 Retired / pensioner 5 Child under the age of 6 6 Other (specify)	How much income (after taxes) did s/he receive from her/his occupation last month? (Rand / month) DK Don't know ---- None	Did s/he receive any grants last month? 1 Disability grant 2 Child support grant 3 Care dependency grant 4 Unemployment insurance 5 Old Age Pension 6 Other (specify) --- None	How much income did s/he receive from grants last month? (Rand / month) DK Don't know --- None
P1							
P2							
P3							
P4							
P5							
P6							
P7							
P8							
P9							
P10							
P11							
P12							
P13							
P14							
P15							
P16							
P17							
P18							

☐ I stay alone.

Interviewer's Name: _____
 Clinic Name: _____

Date: _____
 Patient Folder #: _____

A.5. Are there any children under the age of 18 who have left your household and are now living elsewhere?

☐ Yes ☐ No *[Go to question B.1.]*

A.5.1. Please list the children under the age of 18 who have left the household. *[Do not prompt with options.]*

	Child #1	Child #2	Child #3
Relationship to you			
Age			
Gender			
When did s/he leave? (Month and year)			
Why did s/he leave the household?	-----	-----	-----
<i>Her his parent was too sick to care for her him.</i>			
<i>S he was too sick to stay in the house.</i>			
<i>The family could not afford to pay for her his expenses.</i>			
<i>S he went somewhere to work.</i>			
<i>His her parent(s) died and s/he went to live with other family members.</i>			
<i>Other (specify)</i>			
<i>Don't know</i>			

B. HIV Status and Health Status

Now I am going to ask you some questions about your health.

B.1. What year did you find out that you were HIV+? _____

B.2. Who have you told that you are HIV+? *Read each answer individually.*

	Yes	No
1. Health professionals		
2. Support group		
3. Your partner (<i>if no:</i> do you currently have a partner? _____)		
4. Family members (<i>if yes:</i> how many? _____)		
5. Friends (<i>if yes:</i> how many? _____)		
6. Spiritual leader		
7. Current or former employer		
8. Public disclosure		
9. Other (specify _____)		

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

B.3. Think back to [*yesterday / the last weekday*]. What did you do during the day? Please go through the day and tell me what activities you did and how long you spent doing each activity.

Time	Activity	Time	Activity
5am		5pm	
6am		6pm	
7am		7pm	
8am		8pm	
9am		9pm	
10am		10pm	
11am		11pm	
12 noon		12 midnight	
1pm		1am	
2am		2am	
3pm		3am	
4pm		4am	

Codes:
1 sleep / rest
2 eat
3 housework (clean, cook, laundry, etc.)
4 childcare
5 care for sick or elderly friends/family
6 paid work
7 unpaid work volunteer work
8 transport
9 visit family friends
10 visit healthcare facilities
11 watch TV entertainment
12 other (specify)
13 Don't know don't remember

B.4. How many days during the last month were you too sick to do your normal daily activities? _____

B5. In the last month, did you lose income because of your illness? ☐ Yes ☐ No

B.5.1. If yes, how much income did you lose in the last month because of your illness? R_____

B.6. Over the past month, did any members of your household take time to care for you?

☐ Yes ☐ No [Go to question B6.]

B.7. Who were the people in your household who took time to care for you in the last month?

	#1	#2	#3	#4	#5
1. Code [See question A.1.]					
2. How many days did s/he care for you in the last month?					
3. Did s/he lose income in order to care for you?					
3a. If yes, how many days in the last month?					
3b. If yes, how much income (after taxes) did s/he lose?					
4. Did s/he not attend school in order to care for you?					
4a. If yes, how many days in the last month did s/he not attend school in order to care for you?					

B.8. In the last month, how often did physical disabilities or health problems interfere with your ability to work at a job, look for a job, study, or work around the house?

☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

Interviewer's Name: _____
 Clinic Name: _____

Date: _____
 Patient Folder #: _____

C. Income and Expenditures

Now I will ask you some questions about work. Work can include many things. It can be regular or irregular. It can be 2 days during a month or every day of the week. It can be one hour during the day or all day. For this survey, when I ask you about work, please include in your response anything that you do that earns you money.

C.1. What were your source(s) of income in the last month? Include any work or grants. **Read each item individually. Tick all that apply.**

- ☐ Full-time wage employment
- ☐ Part-time wage employment
- ☐ Casual employment (work that is irregular/short-term)
- ☐ Self-employment (non-wage income-earning activities, including activities like making clothing, crafts, beer, food, etc for sale)
- ☐ Disability grant
- ☐ Other type of grant (specify type and amount per month _____)
- ☐ Other (specify _____)
- ☐ None

C.2. How much money did you receive last month from family members or friends living outside of your household? _____

If interviewee did not indicate a form of employment in question C.1., go to question C.4.

C.3. If you have worked in the last month, what was/were your job(s)? Please include any work that you did for money.

Step 1	Step 2								
Job	How often did you do this work in the last month?				How much did you earn (after taxes) from this work in the last month?				How long have you been doing this work? (Years and months)
	= hours	per day (X)	per week (X)	per month (X)	salary (Rand)	per day (X)	per week (X)	per month (X)	

If interviewee indicated forms of work in questions C.3., go to question C.8.

C.4. What is the reason that you are not currently working? **Do not read options.**

- ☐ I am currently studying.
- ☐ I am currently retired/receiving a pension.
- ☐ I am currently unemployed and would like to work.
- ☐ I currently stay at home by choice/do housework.
- ☐ I am currently receiving a disability grant that provides enough money to support myself.
- ☐ I am currently too ill to work.
- ☐ Other (specify _____)

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

C.5. Are you currently looking for a job (whether full- or part-time wage employment, casual employment, or self-employment)? ☐ Yes ☐ No

C.6. In the last month, did you look for work in any of the following ways?

C.6.1. Respond to a newspaper advertisement? ☐ Yes ☐ No

C.6.2. Knock on factory gates / visit potential employers? ☐ Yes ☐ No

C.6.3. Ask friends or relatives about job possibilities? ☐ Yes ☐ No

C.7. Have you worked before? ☐ Yes ☐ No [Go to question C.8.]

C.7.1. When was the last time that you worked for money? (month) _____ (year) _____

C.7.2. What type of work was your last job?

☐ Full-time wage employment

☐ Part-time wage employment

☐ Casual employment (work that is irregular/short-term)

☐ Self-employment (non-wage income-earning activities, including activities like making clothing, crafts, beer, food, etc for sale)

C.7.3. Why did you stop working at your last job? **Do not read options.**

☐ I lost my job due to illness.

☐ I missed too many days of work.

☐ I lost my job when my employer discovered my HIV status.

☐ I lost my job due to retrenchment. / The company that I was working for shut down.

☐ The employment was only temporary / short-term.

☐ Other (specify _____)

C.8. Has your monthly household income changed in the last six months?

☐ Yes, increased ☐ Yes, decreased ☐ No, stayed the same ☐ Don't know

Interviewer's Name: _____
 Clinic Name: _____

Date: _____
 Patient Folder #: _____

C.9. Please tell me how much your household spent on the following items last month.

Step 1		Step 2
Item	What is your average monthly expenditure on [item]? (Rand/ month) DK = Don't know	Has your average monthly expenditure on [item] changed over the past six months? I = Increased D = Decreased S = Stayed same DK = Don't know
1. Food		
2. Services (electricity, lighting, water)		
3. Savings (stokvels, burial society, insurance, saving schemes)		
4. Transport (to school, work, clinic, etc.)		
5. Health Care (chemist, herbalist, clinic visits, etc.)		
6. Education (school fees, uniforms, materials, etc.)		
7. Rent/bond/accommodation		
8. Other (entertainment, money to family members, and any other expenses)		

Now I am going to ask you some questions about your debt. Please think about whether you have borrowed money from friends, family, banks, money lenders, or stores.

C.10. Do you owe any money?

☐ Yes ☐ No *[Thank the interviewee for her/his time and end survey.]*

C.11.

	To whom do you owe this money? <i>[Check all that apply.]</i>	How much do you owe? <i>[Rand]</i>	What did you spend the money on? 1 basic household expenses (food, water, electricity, hygiene, school, public transport, health care, burial) 2 non-basic expenses (all other expenses, including clothing, furniture, private transport, entertainment, etc.)
1. Friend(s)			
2. Family			
3. Bank(s)			
4. Money lender(s)			
5. Store(s)			
6. Other (specify)			

C.12. Has your debt changed in the last month?

☐ Yes, increased ☐ Yes, decreased ☐ No, stayed the same ☐ Don't know

Thank the interviewee for her/his time and end survey.

Interviewer's Name: _____
Clinic Name: _____

Date: _____
Patient Folder #: _____

Thank you for answering my questions. This is very important for helping to understand how your medicine is affecting your household situation.

[At the baseline:]

I will be individually interviewing a small group of people at greater depth about the questions raised in this survey. The interviews will last about an hour and will happen two weeks after patients begin receiving antiretroviral therapy, and then again after patients have been on antiretroviral therapy for one year. Like your involvement in the surveys conducted today, these interviews would be entirely voluntary and would have no affect on your participation in MSF's antiretroviral programme. The goal of the interviews is to allow us to hear more of the stories of patients receiving antiretroviral therapy. Would you be willing to speak to me in greater depth at a later date about the topics raised in this survey?

☐ Yes

☐ No

Thank you.

Debriefing: Interviewer's Notes (Please explain if there was anything unusual about the interview: noise level, privacy, intrusions, comfort level, etc.)
