THE IMPACT OF ANTIRETROVIRAL TREATMENT ON INDIVIDUAL WELL-BEING IN SOWETO, SOUTH AFRICA

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ABSTRACT

This research explored the short-term socioeconomic effect of antiretroviral treatment (ART) in HIV positive patients attending the Perinatal HIV Research Unit (PHRU) clinics in Soweto & Acornhoek. This study utilised mixed methodology, combining quantitative descriptive analysis with qualitative interviews in two phases.

An overall increase in mean personal and household income (R308 and R130 respectively) following commencement of ART was noted. Mean personal income rose 53% over baseline income. A decrease in the number of meals missed in households was noted in 10% of the sample. The leading themes regarding income were change in employment status and social grants.

Four percent of unemployed patients reported a change in employment status after starting ART despite high unemployment rates in South Africa. Antiretroviral treatments enabled patients to return to formal employment, and in the absence of formal job prospects, informal income generating activities were undertaken. Unemployment was directly related to both ill health and limited employment opportunities. Antiretroviral treatment increased the capacity to seek employment and unemployed individuals were actively searching for work. Nine percent of the sample required less assistance with daily activities once treatment was initiated. An average of 4.6 hours of patient and caregiver time was freed up. Patients noted an improvement in well being, with fewer to no episodes of illness, and improved quality of life from three months after starting ART.

The empirical evidence suggests that individuals gain substantial benefits from being on ART despite the socioeconomic challenges in South Africa. Income changes were directly attributable to changes in employment and social grants, and even though employment opportunities are not readily available in South Africa, improved health led directly to the ability of individuals to participate in economic activity.

DECLARATION

I, Varsha Chhagan, declare that this research report is my own, unaided work. It is submitted in partial fulfilment of the requirements of the degree of Master of Business Administration in the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in this or any other university.

Varsha Chhagan

22 September 2006

DEDICATION

This research is dedicated to all HIV positive individuals who have found hope to live ‘positively’, and to the healthcare workers and funders who work tirelessly to make a difference in the lives of others.

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy/treatment
ARV	Antiretroviral (drug)
BER	Bureau for Economic Research
CCS	Comprehensive Care and Support
CS, C&S	Care and support
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
IEC	Information, education, communication
M & E	Monitoring and Evaluation
OI	Opportunistic infection
OVC	Orphans and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief
PTAP	PHRU Treatment Access Programmes
PLWHA	People living with HIV/AIDS
PHRU	Perinatal HIV Research Unit
SABCOHA	South African Business Coalition on HIV & AIDS
SAG	South African Government
TB	Tuberculosis
UNAIDS	Joint United Nations AIDS Programmes
USAID	United States Agency for International Development
USG	United States Government
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

1 INTRODUCTION

This report describes the findings of research undertaken to assess the short-term socioeconomic impact of antiretroviral treatment (ART) in HIV positive patients. Patient data collected at the Perinatal HIV Research Unit (PHRU) in South Africa (Soweto and Acornhoek) in two programmes, namely the PHRU Treatment Access Programmes (PTAP) and the Comprehensive Care and Support Programme (CCS) was utilised for descriptive analysis (phase one) and followed by in-depth case study analysis (phase two). The research followed both a deductive and an inductive approach based in non-positivist interpretivist philosophy.

1.1 Context

In South Africa, the Department of Health (2005), reported that HIV prevalence among pregnant women attending antenatal clinics in 2005 was 30.2% and the South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey of 2005 reported that the national HIV prevalence in adults 15-49 years of age was 16.2 % (www.hrsc.ac.za). During the early phase of the epidemic, HIV/AIDS was seen primarily as a “health” problem, but as prevalence rates soared globally the macroeconomic impacts became increasing evident to government, private sector businesses and communities (Lewis, 2004:98).

Businesses are being subjected to the pressures of increasingly competitive national and global markets through globalisation and liberalisation of economies, combined with demands from investors and consumers for increased productivity, efficiency, innovation and quality of products and services. In addition, pressures are mounting for businesses to be more responsible and accountable to their wider stakeholders – workforces, suppliers, communities, governments and the general public (UNAIDS, GBC & PWBLF, 2000:19).

Businesses worldwide have responded to the HIV epidemic by establishing strategies and implementing HIV/AIDS workplace programmes. Programmes have ranged from prevention initiatives that provide education and training about the virus and offering employees access to Voluntary Counselling & Testing (VCT) to providing access to care and treatment for HIV positive employees.

The benefits of antiretroviral therapy for the management of HIV have been well established in clinical literature and has been shown to improve HIV related morbidity and mortality (Wood et al, 2003:2419).

UNAIDS & WHO (2005) report that an estimated one million people in South Africa require antiretroviral treatment but only 10-14% of this population has been able to access treatment, leaving some 866 000 people without treatment. The need to scale up access to HIV treatment requires local, regional, national and international efforts across the public and private sectors.

The socioeconomic impact of HIV has been well investigated from a macroeconomic and government perceptive by various researchers, but the impact on business, households and individuals still requires further exploration. The increasing availability of antiretroviral treatment now allows for research into the impact of treatment. While the impact of ART is only estimated to be seen in the long term (three to five years), a short-term assessment of the impact (six to eighteen months) serves to provide some insight into the problem and may assist in advocating for access to treatment.

1.2 Research Problem

The research problem explored in this study is the short-term socioeconomic effect of antiretroviral treatment in HIV positive patients attending the Perinatal HIV Research Unit (PHRU) Clinics in Soweto & Acornhoek, South Africa. This was primarily examined through two sub-problems: what socioeconomic changes are seen on commencement of antiretroviral treatment in an

eighteen-month period and how these changes affect the ability of individuals to participate in economic activity.

1.3 Assumptions

The researcher acknowledges the following assumptions:

1. The research is based on particular programmes at the Perinatal HIV Research Unit (PHRU) and will be applicable to HIV positive patients receiving treatment in other HIV/AIDS programmes in South Africa.
2. Socioeconomic indicators utilised (education level, employment status, individual & household income, living conditions) and the length of time on treatment is valid for this research.
3. Antiretroviral treatment provides some socioeconomic benefits in the long term.
4. Extraneous social, cultural and economic factors influence the research (poverty, income inequality, gender inequality, unemployment and cultural issues).

1.4 Delimitations

The scope of the research entailed descriptive analysis of secondary data (existing database of information collected in the programmes at PHRU) and qualitative analysis by way of patient case studies. The research investigated the research problem in the Comprehensive Care and Support (CCS) and the PHRU Treatment Access Programmes (PTAP) at the PHRU sites based at Chris Hani Baragwanath Hospital in Soweto, and at Tintswalo Hospital in Limpopo, South Africa. Data in these programmes was collected by way of structured interviews. The design of the research did not offer for any control of extraneous variables. The research cannot control for other HIV affected individuals in the households of the participants being interviewed. The research is undertaken within the context of high unemployment rates, poverty and income inequality in South Africa. Only adult patients (16 years of age and older) are included in this research.

1.5 Relevance of Research

Barnett & Whiteside (2000) argue that socioeconomic impact studies serve as tools for advocacy. If a measurable and predictable impact can be established then people may be convinced of the problem and be encouraged to engage in prevention. It also serves to establish the location, scale and form of a problem to assist in planning. Hence, these studies serve a dual purpose, providing the rationale for both prevention and mitigation.

Booysen et al (2002) also identify the need for assessment of the socioeconomic effect of HIV/AIDS at the micro-level and add that this analysis should include determining how the disease affects the economic decisions and position of individuals and households over time.

Although this research does not entail an econometric impact analysis offering predicative patterns, it serves a key purpose in describing trends in morbidity, employment, education and income when individuals have commenced antiretroviral treatment.

The provision of ART provides millions of infected individuals with hope for a better quality of life and an extended life span. While the impact of HIV has been well researched and documented, there is little information available on the socioeconomic impact or effect of ART. It is crucial to determine both the short and long term impact of ART to further motivate for access to treatment, encourage business to provide access to treatment in their workplace programmes and donors to evaluate the impact of their funded programmes. On an individual level, it is critical to highlight to infected and affected persons the socioeconomic effect of treatment to enable people to overcome the fear of stigma and discrimination and encourage them to access treatment programmes.

1.6 Background

According to the latest statistics published by UNAIDS/WHO (2005) it is estimated that the total number of people living with the human immunodeficiency virus (HIV) is 40.3 million. Sub-Saharan Africa which houses 10% of the world's population is estimated to be home to more than 60% of all people living with HIV. In South Africa, the Department of Health, reports that HIV prevalence among pregnant women attending antenatal clinics has peaked at 30.2% (Department of Health South Africa, 2005).

UNAIDS/WHO (2005) reports that in the past two years, access to antiretroviral treatment has improved markedly. The number of people receiving HIV antiretroviral therapy in low and middle-income countries has tripled since the end of 2001. Yet, at best, it is estimated that only one in every ten people in Africa and one in every seven people in Asia in need of antiretroviral treatment were receiving it in mid-2005. On the other hand, over one million people in low-and middle-income countries are now living longer and better lives because they are on antiretroviral treatment.

WHO (2003) adds that there is growing availability of treatment and enhanced community outreach can lead to more openness about AIDS, which can help break down stigma and discrimination. A health survey conducted after the introduction of antiretroviral programmes in Khayelitsha, South Africa, found higher condom use, willingness to join AIDS clubs, and readiness to be tested for HIV compared to other sites surveyed.

Barnett & Whiteside (2002) emphasise that the HIV/AIDS epidemic increases morbidity and mortality in populations in their most productive years. This means that corporate and small businesses will feel the impact of HIV/AIDS by reduction in the productivity of individual workers, raising costs and the changing operating environment through increased absenteeism, early retirement due to ill-health, increased costs of recruitment and training, increased size of workforce to cover absenteeism & low productivity,

increased wages if skilled workers become scarce, and the lack of funds from reluctant investors.

In addition, business needs to address the impact of HIV/AIDS on the markets in which they operate. HIV/AIDS could affect markets by reducing the number of consumers or their capacity to purchase products. The demographics of HIV/AIDS reduces the number of consumers in the 25-49 year age groups affecting the demand for consumer goods (Barnett & Whiteside, 2002: 248).

This has led many companies to employ strategies to mitigate the impact of HIV/AIDS in the workplace. Barnett & Whiteside (2002) argue that while the response to HIV/AIDS is slow, many companies have responded by evaluating the direct, indirect and systemic costs of HIV/AIDS.

Dickinson (2003) stresses that guidelines for responding in the workplace have advocated that companies balance prevention of HIV infection with care for those already infected. One of the central dilemmas in providing treatment has been the cost of drugs. Nattrass (2003) adds that as a result of the reduction in prices of antiretroviral treatment in 2001, businesses undertook to start supplying it, either directly or indirectly through medical aids, to their workforce.

Antiretroviral drugs have a dramatic effect on HIV positive patients, by creating the conditions for substantially prolonging life and enabling life to be fully active and therefore economically productive. It is for this reason that many large corporations have programmes that include the provision of ART to their core workforce (Love, 2004:642).

Harmony and Anglo Gold are two mines cited in the SABCOHA & BER Report (2005) as having a HIV prevalence of 30% among their respective workforces and subsequently both companies have implemented programmes that provide antiretroviral therapy for their employees. Brian Brink, the Vice-President of Health at Anglo American, is cited in the report, as saying access to antiretroviral treatment is the “most effective weapon for banishing fear and

ignorance and for preventing stigma and discrimination. With early access to effective treatment, there will be no opportunistic infections, very little absenteeism, no loss of productivity and little need for hospital or home-based care. The economics of providing access to treatment in the workplace are self evident" (Ellis & Terwin, 2005:6).

Yet Ellis & Terwin (2005) report in the same study that assessed the impact of HIV/AIDS on 445 companies in South Africa, that only 38% of financial services companies and 26% of mines surveyed provide ART in the workplace, and 15% or less of the respondents in the other sectors provided HIV treatment. This indicates that the response to HIV from the business sector is rather slow and highlights the need for further advocacy for the provision of ART in workplace programmes.

The Perinatal HIV Research Unit (PHRU) is one of the major AIDS research centres in Africa and leads studies into HIV prevention, care, support and treatment. It is based at the Chris Hani Baragwanath Hospital in Soweto, South Africa. The PHRU endeavours to reduce the impact of the HIV epidemic on South Africans in collaboration with key stakeholders. Innovative, high quality and relevant inter-disciplinary research is lead in a dynamic environment. Research is conducted under the highest ethical standards and respects the rights of people and communities. The PHRU is involved in research, training, policy-formation and advocacy concerning HIV-positive people and their children. In addition, the PHRU has extended beyond research into areas of prevention of mother-to-child transmission, treatment trials in adults and children, treatment research, prevention research, and psychosocial research (www. phru.co.za).

The Comprehensive Care and Support (CCS) programme at the PHRU is funded by the United States Agency for International Development (USAID). CCS is a primary health care nurse-delivered service that is investigating an appropriate model of comprehensive care for those in the earlier stages of HIV. The PHRU in partnership with Rural AIDS Development Action Research based at Tintswalo Hospital in Limpopo Province, have over the past years

established wellness clinics for people with HIV. The model includes regular monitoring of HIV, diagnosis and treatment of sexually transmitted infections, TB screening and referral for treatment if required, family planning and opportunistic infection prophylaxis. The objective of this programme is to set up a cohort of people living with HIV who access a package of primary care interventions including transition onto antiretroviral treatment when clinically appropriate. Data continues to be collected from patients who have been transitioned onto antiretroviral treatment (Martinson & Pronyk 2005).

The President's Emergency Plan for AIDS Relief (PEPFAR) funds the PHRU Treatment Access Programme (PTAP). Patients are moved onto this programme from the CCS programmes when the criterion for starting treatment has been met. This programme has made antiretroviral treatment available to over 1000 patients.

2 LITERATURE REVIEW

This literature review examines the socioeconomic impact of HIV/AIDS and within this framework reviews the impact at the macroeconomic, household and individual level. Literature on the socioeconomic impact of antiretroviral treatment (ART) is extremely limited and this research endeavours to address this gap offering direction for future research.

The impact of HIV/AIDS is of grave concern to all stakeholders. Nattrass (2004a) stresses that South Africa faces two major economic and social security challenges: large scale unemployment and the AIDS pandemic. Barnett & Whiteside (2002) add that the HIV epidemic increases morbidity (illness) and mortality (death) in populations at precisely the ages where normal levels of morbidity and mortality are low. Therefore impact of the epidemic occurs at different levels: the household, community or nation.

2.1 Macroeconomic Impact

Numerous studies have been conducted to assess the macroeconomic impact of HIV/AIDS globally. Many have been conducted in developing countries and have included econometric techniques and modeling to establish the projected impact of the HIV epidemic.

Bonnel (2000) believes that the four factors that explain why HIV/AIDS affects social and economic development to such an extent are:

- The speed and scale of the epidemic has been worse than the projections of 1990's.
- HIV/AIDS reduces the stock of human and physical capital as it affects adults in their productive years and undermines incentives to save and invest.
- AIDS destroys social capital by straining existing institutions at community and national level.
- Feedback effects further amplify the impact of HIV/AIDS on economic growth.

Smit, Visagie & Laubscher (2001) expand further and identify five broad economic key macroeconomic impact channels of the HIV epidemic as:

- A lower overall population and labour force, affecting both the production side (the economy's production potential) and the expenditure side of the economy
- Direct costs to the private business sector, e.g. increased contributions by firms to their employees' pension, life, disability and medical benefit schemes
- Indirect costs to the private business sector, e.g. firms having to face the costs associated with increased absenteeism, training, and recruitment. Reduced labour and multi-factor productivity could present other indirect costs to firms
- Increased government expenditure due to the higher direct and indirect costs (similar to the case for business), the increased demand for public sector health services and the orphan legacy of the HIV/AIDS epidemic
- *And*, households are likely to face additional out-of-pocket spending on health care products and services as well as for funeral services.

The main economic variables identified by Bonnel (2000) that are the key determinants of the HIV epidemic are life expectancy, labour migration, human capital, income inequality and gender inequality. Because access to health services is generally dependent on the level of income, there is a positive association between income inequality and HIV/AIDS.

Arndt & Lewis (2000) reported in a study that the impact of the AIDS epidemic in South Africa could be "substantial". By the year 2010, the level of GDP could be lower by 17 percent due to HIV/AIDS while the level of per capita GDP could be lower by 7 percent. About half of the decline is attributable to the increase in current government spending to pay for health care associated with the epidemic and another third is attributable to lower productivity.
Bonnel (2000) adds that HIV/AIDS' extraordinary impact on development is due to its ability to undermine the three main determinants of economic growth, which are physical, human and social capital. HIV/AIDS adversely

affects macroeconomic outcomes as it worsens fiscal deficits and reduces the macroeconomic management capacity of governments. The World Bank states that the macroeconomic performance of developing countries is negatively affected by the HIV/AIDS epidemic. The impact on physical capital over time is the extent to which HIV/AIDS worsens the government budget and reduces domestic savings. The increase in expenditure in health will be due to treatment and care costs. The impact on human capital is more pronounced in the initial stages of the epidemic than over the long term.

Because HIV/AIDS affects the social structure of local communities it erodes existing social network and traditional support mechanisms. HIV reduces the skilled labour force, it adversely affects the ability of government to enforce effective regulation and legal framework. The most likely consequence would be an increase in transaction costs and a reduced efficiency in production. The large number of orphans who might grow up without the support and guidance of adults may worsen insecurity and affect foreign investment ratings (Bonnel, 2000).

Greener et al (2000) quantify this in their analysis of the impact of HIV/AIDS in Botswana that the national income dependency due to HIV/AIDS could increase by 20% in ten years. This translates into every income earner could on average expect one extra dependent.

Geffen, Nattrass & Raubenheimer (2003) found that the net costs to the South African Government are significantly lower than the direct costs of providing ART and that because people on ART experience fewer opportunistic infections and therefore require less treatment, the government incurs further savings.

Smit, Visagie & Laubscher (2001) conclude that the macroeconomic impact of the HIV/AIDS epidemic cannot be ignored. The overall result is a negative financial impact, which has negative feedback effects on economic growth and job creation. This is exacerbated by the negative impact on savings, in

turn, having negative implications for fixed investment and South Africa's balance of payments constraint on economic growth.

UNAIDS, GBC & PWBLF (2000) report that for many businesses the impact of HIV/AIDS is severely constraining their ability to be competitive, while for others the potential risks are significant in both high and low HIV/AIDS prevalence regions. HIV/AIDS is an issue that goes to the very core of business practices whose effects are evident on two levels, the macroeconomic and the individual company levels, both of which require urgent responses if businesses are to remain competitive.

The macroeconomic impact of HIV/AIDS is important and needs to be identified as it has a considerable effect on business operations through its influence on markets, savings, investment, services and education. HIV/AIDS primarily affects people within their most productive years of life and through reduced earnings (as a result of illness), care demands, higher expenditure on health care and premature death, the result is a reduction in savings rates and disposable income. In the long-term this reduces the market size for business, particularly in markets outside of the basic necessities of food, housing and energy, and reduces the total resources available for production and investment, thereby declining economic growth (UNAIDS, GBC & PWBLF, 2000:13).

Because of the higher morbidity and mortality associated with HIV/AIDS, no sector of the economy is immune to the impacts, particularly as a result of the reduction in available productive and skilled labour and investment. The collective effect of this is increase in the broader service and production costs to business, particularly through the effect on sectors such as transport and the utilities that are essential inputs for most market activities. Business is also dependent on the education sector for its future workers, managers and business leaders. This sector is acutely impacted by HIV/AIDS through the reduced numbers of experienced teachers and numbers of children attending school (due to lower household incomes, caring for family members,

becoming orphaned and HIV/AIDS infection) (UNAIDS, GBC & PWBLF, 2000:13 -14).

Rosen et al (2004) warn that companies may not see the costs of an infected HIV positive employee until 5 to 10 years because of the long latency period of HIV. Should the company retain the employee on its workforce then the company risk entails acquiring the future costs associated with the infection. Companies should estimate costs on the basis of incident infections so that expenditure on HIV programmes can be treated as potentially profitable investments rather than recurrent costs.

A number of companies have provided antiretroviral therapy to their employees. Given the negative impact of the epidemic on productivity and sustainable profits, there is a clear business case for offering access to treatment (UNAIDS, 2005: 6).

UNAIDS, GBC & PWBLF (2000) reports that Volkswagen, Brazil has established HIV/AIDS care programmes in order to manage increased costs (a result of frequent illness and hospitalisation and loss of employees). The company provides assistance and care by giving employees access to antiretroviral drugs, regular viral load tests, and referral to specialist hospitals and home care treatments. This is combined with prevention and health education and counselling. The company reports that the programmes has led to reduced rates of hospitalisation by 90 percent and costs as a result of HIV/AIDS have been reduced by 40 percent.

UNAIDS (2005) report that three companies in South Africa who's HIV/AIDS policies and programmes in South Africa are viewed as pioneering and examples of best practice are Anglo American, BHP Billiton and Eskom. Brink (2003) from Anglo American Corporation reported that the company's response to HIV/AIDS combines clear strategy, strong leadership and effective programme implementation. The company links prevention efforts to care and support initiatives through voluntary counseling and testing (VCT). It is estimated that ten percent of the 30 000 HIV positive employees qualify to

commence antiretroviral treatment. Initial reports of the treatment programmes were encouraging and reported that 97 percent of the 7000 employees receiving treatment were back at work.

ILO/UNAIDS/GHI (2003) reports that DaimlerChrysler South Africa estimates that the current value cost of an additional HIV-infected employee, depending the employee's pay category, ranges from US$17,000 to US$126,000. It is also reported that one trigger for the Heineken company to fund HIV treatment was the need to relieve its managers of the "intolerable stress" of making decisions that affect job security, health and even survival of their employees and their families. Daimler Chrysler and Heineken also extended access to antiretroviral treatment to redundant and dismissed employees.

UNAIDS (2002) reports that Debswana, a diamond mining company in Botswana, commissioned an institutional HIV/AIDS audit and two actuarial studies that led to the company's decision to provide antiretroviral treatment to employees and the creation of a trust fund for the provision of drugs and monitoring blood tests in 2001. The executive committee recommended this to the board as part of a total strategy to care for and support HIV infected employees and to improve their total quality of life. It was also seen as a way of mitigating human and systemic costs, which include a decline in morale, motivation, workforce performance and cohesion, the loss of organisational memory and the psychological impact of increased illness and death.

2.2 Household and Individual Impact

Several household studies have been conducted to assess the impact of the HIV/AIDS epidemic at the household level. Naidu & Harris (2005) reviewed thirty-two studies on the impact of HIV/AIDS on households. Of these four were comprehensive surveys of social and economic impact of HIV/AIDS morbidity and mortality. They reported that both the direct and indirect costs of HIV/AIDS to households increase with severity of illness and ultimately death.

The impact of HIV/AIDS on the individual level is perhaps more difficult to understand. It is a personal experience dependent on a combination of how individuals cope with the infection, the clinical progression of the disease and the living standards or environment of that individual.

Desmond, Michael & Gow (2000) argue that because HIV/AIDS causes significant increases in illness and death in prime age adults, the affect is seen in both households and communities. The documented economic impact at the household level is decreased income, increased costs, decreased productive capacity and changing expenditure. The authors identify three coping strategies that include the altering of household composition, the withdrawal of savings or the selling of assets and receiving assistance from other households. The decease in income together with the increase in health care expenditure leads to a fall in expenditure on basic needs. This shrinkage and reallocation of the household budget reduces food security thereby increasing the chances of malnutrition and sickness of other members in the home.

In a longitudinal controlled study of households affected by HIV in the Free State, South Africa, Booysen et al (2002) found that HIV affected households were on average slightly larger in size with higher dependency ratios than non-affected households. Illness and death in the affected households occurred mainly among economically active individuals between the age of 15 and 49. Investigation revealed that affected households were poorer than non-affected households regardless of whether income and expenditure was measured at the household or individual level. Furthermore, affected households were more dependent on non-employment sources of income with only a small proportion of the income from employment. In these households, less money was spent on food than non-affected households. The study also found that the total cost of morbidity to households was relatively low where unemployment levels were very high. Ill household members were primarily cared for by family members with no direct loss of income reported. A larger number of children in affected households were not

attending school and orphans were found to be sheltered in both affected and non-affected households.

The effects of HIV illness and death in households depend on: the number of cases the household experiences, the characteristics of the deceased individuals (age, gender, income), the household's composition and asset array, the community's attitudes towards helping needy households and the availability of resources in the community and the broader resources available for assistance to households (non-governmental and community-based organisations) (Barnett & Whiteside, 2002:185-186).

Redclift & Mingione claim that HIV/AIDS can impact upon the different ways in which households earn income. These include formal employment or self-employment by or under a registered entity, informal employment or self employment with a non-registered entity and illegal activities, work which is not exchanged for income (e.g. taking care of sick household members) and finally home production for self-consumption (e.g. cultivating vegetable gardens) (Naidu & Harris, 2005: 536).

Adult illness or death reduces household income. Less labour is available because the affected individual may not be able to work and also because time of others may be diverted to care for the sick. Illness also increases household expenditure on medical care, food and washing materials (Barnett & Whiteside, 2002:189).

In addition to the loss of income and changes in spending priorities, surviving household members may experience other consequences of illness and death. The surviving spouse may have to seek employment to supplement income or leave work to care for the sick. Time may be reallocated on various household activities and new members may be brought into the household to help care for sick members. Children may be sent to extended family members for care (Naidu & Harris, 2005: 538).

In rural Limpopo, South Africa, Oni et al (2002) reported that the average annual income was approximately 35 percent lower in households affected by HIV/AIDS than in non-affected households and Morris, Burdge & Cheevers (2000) found that the impact of HIV on individual households to be as much as a 67 percent decrease in average income with one HIV infected household member. Abt Associates Inc (2002) confirmed this impact on income by stating that two thirds of the 700 households surveyed reported a loss of income as a consequence of HIV/AIDS and almost half reported not having enough food.

Greener et al (2000) studied the impact of HIV/AIDS in Botswana and predicted that the overall per capita income of households will be reduced by ten percent as a result of HIV/AIDS and the loss of income earners in the absence of any effects of unemployment or wages. Lundberg, Over & Mujinja (2000) add that HIV/AIDS usually strikes prime-age adults who are at the peak of their productive and income earning years and hence, who are often heads of families. Other things being equal, fatal illness increases household expenses (for healthcare and ultimately funerals) at the same time as it reduces household income (due to diminished labour time).

Bachmann & Booysen (2003) studied 404 HIV-affected and unaffected households and found that HIV/AIDS affects the health and wealth of households aggravating pre-existing poverty. Ill members of affected households required more caring support from their households than unaffected households. 35% of affected households needed someone to accompany an ill member to a health service and the median number of hours that home carers spent with ill members was 5 hours per day. The study found that over six months, household expenditure decreased significantly more rapidly in affected households than in unaffected households. Per capital income in households with at least one ill member was 26% lower than in unaffected households.

On the twelve and eighteen month follow up on the same households, Bachmann & Booysen (2004) found that affected households were less likely

to recover from illness, less able to perform usual tasks and required more care at home. The individuals in the affected households were more likely to need admission to hospital and more likely to lose income while ill.

Naidu & Harris (2005) cite Lundberg & Over who identify that the way households cope with the financial burden of HIV/AIDS is to generate income through various “non-earned” means such as remittances (transfers), special events (marriage), donations and social grants. Furthermore, in poorer households non-earned income may form a significant portion of the total household income.

Naidu & Harris (2005) argue that the extent to which the impact of HIV/AIDS is felt at household level depends on the use of survival strategies. Booysen et al (2002) report that affected households in the Free State saved 40% less and 30% borrowed money compared to non-affected households. The majority of households borrowed money to cover expenses associated with illness and death.

The Impact of HIV/AIDS could either increase or decrease the savings of households. In the face of adult family member’s illness, the predominant development seems to be that households experience a fall in income, which forces them to deplete their savings and/or assets. If households view the risk of contracting AIDS-relating diseases as significant, then household’s savings could increase to cover costs of medical expenses later on in life. (Bonnel 2000: 825). Longer term impacts may be negative if assets and savings are not replaced or if children drop out of school to take care of the sick, start working or because they are unable to pay school fees (Naidu & Harris, 2005: 540-541).

Booysen et al (2002) state that indirect costs of HIV/AIDS are commonly associated with loss of earnings to the sick person, and Naidu & Harris (2005) add that a sick individual loses income in one of two ways, reduced productivity and/or loss of employment. Desmond et al (2000) report that the distribution of the impact of the AIDS epidemic falls unevenly among gender.

Women are documented to have higher infection rates and bear a disproportionate burden of care of HIV positive people.

A key determinant of economic independence is education. Education is associated with lower prevalence rates. Education operates to raise the costs of the becoming infected and particularly if it includes sexual education, it will improve the knowledge of the risks entailed by unprotected sexual relations. Both factors increase the incentives to invest in HIV prevention activities and account for the broad negative relationship between education and HIV. Better-educated workers have more incentives to invest in HIV prevention methods than less educated workers because the cost of HIV/AIDS infection rises with education and training. Survival strategies of households that are already poor often involve taking children out of school, increasing the likelihood that these children will have lower income than otherwise (Bonnel, 2000: 827).

A direct long-term consequence of the HIV/AIDS epidemic is the large number of orphans that are left behind due to deaths of both parents. Children within households face problems both during the illness of an adult in the households and after the death of the adult. These problems include the withdrawal of children from school, decreased access to food and medicines, and psychosocial neglect. After the death of a parent, an orphan may face an additional set of problems, such as a lack of accommodation and income, theft of property and inheritance, sexual abuse, economic exploitation and an additional decline in health status. Orphaned children may be moved to the house of a relative, but there is also evidence of an increase in the number of child-headed households. In addition, death of a parent may lower the nutritional status of surviving children by reducing household income and food expenditure along with a reduction in adult attention to child rearing. An adult death may also reduce school enrolment by reducing the ability of families to pay for schooling, or create a demand for child labour. Orphans that are not absorbed into extended family structures may face life inside child-headed households or on the streets (Desmond et al, 2000:14-16).

However, antiretroviral treatment provides hope for those affected by HIV/AIDS. Many workers are able to access ART through their employers or medical schemes. Others live in urban areas and are able to queue for treatment sites at large urban hospitals but people without jobs have neither access to earned income nor life-prolonging medication (Nattrass, 2004a: 88).

Cleary, Boulle, McIntyre & Coetzee (2004) conducted a economic evaluation using Markov modelling to establish the cost-effectiveness of ART in a South African township and found that the average life expectancy was 8.33 years on ART and only 2.27 years for patients not on ART. Patients reported higher quality of life on ART than those not on ART. Effectiveness of ART was measured in terms of quality-adjusted life years (QALYs) gained, a common outcome measure, which combines both the quality and quantity of life. The incremental cost per QALY gained on ART indicated that antiretroviral treatment is efficient in economic terms. In addition, the clinical results of this study demonstrated the potential for ART to delay many of the individual and societal consequences related to early mortality, by extending and improving quality of life.

Infected individuals in the absence of treatment can expect to experience periods of illness that increase in frequency, severity and duration. For most individuals as the CD4 counts decline, so does their state of health. These individuals will also face an impact on the resources they have at their disposal (Barnett & Whiteside, 2002: 183).

The literature reviewed has highlighted the documented impact of HIV/AIDS at the macroeconomic, household and individual level. The effects of antiretroviral treatment have to date mostly been documented from a clinical perspective. The availability of ART in the workplace has led to improvement in health as discussed above, however the area of socioeconomic effects has not been widely studied. This research will serve to descriptively investigate the socioeconomic changes seen in individuals who have commenced antiretroviral treatment.

3 RESEARCH METHODOLOGY

This study examines the short-term socioeconomic effect of antiretroviral treatment in HIV positive patients attending the Perinatal HIV Research Unit (PHRU) clinics in Soweto & Acornhoek, South Africa. The research utilises mixed methodology in two distinct phases. Existing data collected at the PHRU in the CCS and PTAP programmes is descriptively analysed in phase one of the research. Qualitative analysis by way of case studies of selected participants in Soweto is utilised to gain insight into the suggestive trends in phase two.

Sandelowski (2000) acknowledges that researchers are increasingly turning to mixed method techniques to expand the scope of research, deepen their insights and improve the analytic power of their research studies. Furthermore, at the technique level mixed methods serve the purpose of complementarity by clarifying, explaining or otherwise more fully elaborating the results of analyses.

3.1 Research Philosophy

This research is based in the non-positivist, interpretivist paradigm of research. Interpretivism provides rich insights into the complex world of business. Business situations are complex and unique and research in this context is a function of a particular set of circumstances and individuals. The interpretivist position undertakes to explore the subjective meanings motivating people's actions in order to be able to understand these (Saunders, Lewis & Thornhill, 2003:84).

Ulin, Robinson, Tolley, & McNeill (2002) state that the types of research questions that arise in an interpretivist framework are mainly those that address the 'why', 'how' and 'under what circumstances' rather than 'what' and 'how many'? The methods associated with this perspective enable participants to speak freely and to comprehend the investigators search for insight into a phenomenon that the participant has experienced. The three

components of the interpretivist framework are the subjective perceptions and understandings, which arise from experience, objective behaviours and context. Qualitative analysis allows the researcher to link findings from these three components to investigate the multiple relations among them.

Falconer & Mackay (1999) add that for the non-positivist, the social world is relativistic and therefore can only be understood from the perspective of the individuals who are directly involved in the activities being studied.

3.2 Research Approach

This research follows both a deductive and an inductive approach. Hyde (2000) states that there are two general approaches to reasoning, which may lead to acquiring new knowledge. Inductive reasoning commences with observation of specific instances and seeks to establish generalisations. In contrast, deductive reasoning commences with generalisations and seeks to see if these generalisations apply to specific instances. Hyde argues that the adoption of formal deductive procedures can represent an important step for assuring conviction in qualitative research findings.

Phase one of this research follows a deductive approach while phase two employs an inductive approach. In phase two, additional data collected is analysed to gain further insight into the descriptive results obtained from phase one analysis. Saunders et al (2003) state that an inductive approach in research allows for the suggestion of alternative explanations, places the research findings within the context in which events are taking place, provide an understanding of the meanings humans attach to events and allow for the collection of qualitative data making the researcher part of the research process.

3.3 Research Strategy

According to Babbie & Mouton (2001) research can serve one or more of three purposes; exploration, description and explanation. This research is an

empirical study, which entails descriptive analysis of data and qualitative case study analysis. This study is both descriptive and exploratory.

Saunders et al (2003) state that exploratory studies provide valuable means of gaining insights into a particular situation. It also allows for flexibility and adaptation to change as data and insights appear and suggest particular direction.

Falconer & Mackay (1999) describe qualitative research as a field of study that include studying things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.

3.4 Research Design

This study was conducted in two phases.

- Phase one involved descriptive analysis of secondary data (existing data already collected at the PHRU in the CCS & PTAP programmes), which had not been analysed as yet.
- In phase two qualitative data was collected and analysed. A small sample of participants from the CCS and PTAP cohort were selected for qualitative interviews.

Babbie & Mouton (2001) caution against the use of secondary data as it provides the researcher with less control over the production of the data, because someone else has already produced the data.

The original CCS & PTAP programmes have a time-series design. Leedy & Ormrod (2005) state that this design consists of making a series of observations (measuring the dependent variable on several occasions), then introducing an intervention or other new dynamic into the system. Additional observations are then made. The intervention in this research is the commencement of antiretroviral treatment. In this design the sequence of observations made prior to starting treatment is referred to as baseline data

and compared to the most recent data collected. There are no control groups in both the CCS and PTAP programmes.

Leedy & Ormrod (2005) warn that the major weakness of this design in the absence of a control group is the possibility that some other unrecognised event may occur at the same time that the experimental intervention (antiretroviral treatment) does. If this other event is actually the cause of the change, then any conclusion that the intervention has brought about the change will be an erroneous one.

To address this concern qualitative analysis was conducted to explore the suggestive trends established in the descriptive analysis of the data. Twenty one patient case studies are supported by three PHRU staff interviews.

3.5 Time Horizons

This study incorporated analysis of longitudinal data collected on participants in the CCS and PTAP programmes at the PHRU, which has been collected over a period of approximately 36 months. The research is a study of data collected in a type of longitudinal study called a cohort study that examines a specific sub-population (HIV positive patients that commence ART) as they change over time. Data collected for each participant on entry to the programme has been collected and is treated as baseline data and then compared to data for the same patients on ART for ≥ 3 months, ≥ 6 months, ≥ 9 months, ≥ 12 months, ≥ 15 months and ≥ 18 months. On completion of the descriptive analysis, major findings are explored through patient case studies.

3.6 Data Collection

The research population (HIV positive patients) are voluntary patients that attend the CCS and PTAP programmes at the PHRU clinics. Both programmes have received ethics approval from Witwatersrand Research Ethics Committee. Another application for ethics approval was submitted and approved in June 2006 to conduct this research. Leedy & Ormrod (2005)

recommend that human subjects in research be ethically investigated ensuring protection from harm, informed consent is obtained, and the right to privacy should be maintained.

Phase one data was collected by the PHRU and each patient signed a consent form to enter the programme prior to any collection of data. Confidentiality of all study participants is strictly maintained and standard operating procedures are enforced to avoid breaches in confidentiality. In phase two, patients also signed a consent form (Appendix C) to participate in the study and agreed to be interviewed.

As suggested by Leedy & Ormrod (2005), the PHRU ensures that all individual participants are assigned a unique identification number, and the list of names and numbers are kept in locked filing cabinets. Furthermore, counselling, interview and tracing staff are trained on the procedures for maintaining confidentiality of their clients, and field workers are trained in approaches to actively seek out participants for return visits without divulging the identity of the project to others in the community. The same process was followed for qualitative interviews in phase two of the research.

3.6.1 Phase One – The Database

The data for phase one of the research had already been collected at the PHRU in the CCS cohort study. Patients have been interviewed at each PHRU clinic visit and information has been collected in a standardised study Case Report Form (CRF). A CRF has been kept for all clients and updated at each visit (three to seven monthly). A visit CRF has been kept to record details of individual consultations at each site.

The patients have been interviewed by primary health care nurses who administer patient care and collect the required data in the standardised documentation. The nurses speak English, isiZulu, Sesotho and converse in the preferable language of the patient. The information collected from these sources is entered into the PHRU's comprehensive database for evaluation

and analysis. Individual level and group level statistics are both collected. The data entry follows research standards where two separate individuals enter the data to reduce the likelihood of typographical data entry errors (Martinson & Pronyk, 2005).

3.6.1.1 Sampling

Purposive sampling was used in this research. In purposive sampling people or other units are chosen for a particular purpose (Leedy & Ormrod, 2005). The existing database consists of information collected on over 3000 HIV positive patients who are in the CCS programme and those that have commenced ART in the PTAP programme.

There were approximately 642 adult patients in the CCS database that have commenced antiretroviral treatment. Purposive sampling was utilised for the final dataset. The patients in the database were selected if both baseline information and recent patient follow up information was collected. Patients were excluded from the sample if no baseline or follow up data was available, if the patient started then stopped treatment, and if the collected data for visits was incomplete. The final analysis was conducted on a sample of 249 patients. This sample was stratified into groups of patients based on the length of time they have been on antiretroviral treatment. Patients were assigned to groups if they have been on ART for ≥ 3 months, ≥ 6 months, ≥ 9 months, ≥ 12 months, ≥15 months and ≥ 18 months.

3.6.1.2 The Instrument (Case Report Form – CRF)

The CCS and PTAP programmes use CRF's to collect *standardised* patient information. The data that was analysed in phase one has been captured through the programme on a CRF. The CRF has been designed by the programme directors in conjunction with the programme's data managers. The CRF is standardised with strict version control and change authorisation. The CRF has been developed to minimise interviewer bias and error by utilising response categories for closed ended and fixed-alternative questions. Most answers are variables that have two or more discrete or continuous

variables. These variables are both numerical and categorical. The numerical data include nominal and ratio data. Blank spaces have been provided for non-listed options under the option: other and for certain other measures (income). Close-ended questions require explicit answering by using check boxes.

This research focuses on information collected in the CRF from the CCS cohort study. The CRF includes demographic, socioeconomic and clinical information on patients. Selected information from this CRF was utilised in this study and have been highlighted in Appendix A. Information collected at baseline includes basic demographic information, and includes age, level of education, occupational status, type of housing, income and sources of income, household structure and size, and the level of assistance required for daily activities. The date that ART is started is recorded. At follow up visits, any change in baseline information is collected as well as change in employment, housing, household head, marital status, or education. Information on individual and household income is recorded. The number of meals missed in the household is also recorded.

3.6.1.3 Validity

The validity of a measurement instrument is the extent to which the instrument measures what it is supposed to measure (Leedy & Ormrod, 2005: 28). The CRF used in the collection of data for the PHRU programmes have face validity as on the surface, it appears to be measuring particular variables. Staff members also use it uniformly. The CRF also has criterion validity as it reflects economic status by measure of personal income, household income, housing material, water supply source and report of missed meals. The same standardised instrument (CRF) is used for both pre-test and post-test visits. This ensures that prejudice is reduced. The training of the nursing staff on the administration of the CRF in conjunction with the verification and resolution of data queries by the data staff ensures internal invalidity.

3.6.1.4 Reliability

Reliability is the consistency with which a measuring instrument yields a certain result when the entity being measured hasn't changed (Leedy & Ormrod, 2005: 29). The Standard Operating Procedures for data collection at the PHRU offer measures to ensure internal consistency reliability and test-retest reliability. The reliability of the instrument is ensured by:

- using standardised CRF's
- ensuring the reliability of research workers (primary health care nurses) who are experienced and have attended training in research and good clinical practice techniques
- clarity is sought by a data administrator in the case of ambiguity or incorrect coding
- interpretation bias is minimised by the use of response categories. Information is collected in the written sequence of the CRF, ensuring that the interviewers do not introduce subjectivity into the responses.

3.6.2 Phase Two - Qualitative Interviews

On completion of phase one analysis of the existing database, 21 patients were selected and scheduled for interviews. All participants were accessible by telephone and letters and were contacted by the PTAP programme staff and asked to participate in the research. Patients were requested to sign an informed consent granting permission to be interviewed and tape-recorded. The interviews were conducted over a six-day period at the PHRU clinic in Soweto, in a private consulting room.

3.6.2.1 Sampling

Non-probability sampling was used to collect data for the case studies. Only patients attending the PHRU clinic in Soweto were considered for interviews and those attending the clinic in Acornhoek excluded. Criterion sampling, which is a type of purposeful sampling was utilised. Patient case studies met the criterion of suggesting strong data trends in phase one in order to be selected for interviews. This enabled exploration of the "how" and 'why" of

such findings. This sample was further stratified into groups that reflect the length of time patients have been on antiretroviral treatment. Interviews lasted about one hour and further clarification was sought telephonically if needed.

3.6.2.2 The Interview

Semi-structured face-to-face interviews were used to collect the data. An interpreter (trained and qualified for qualitative interviewing at the PHRU), fluent in isiZulu and Sesotho, assisted with the interviews. Each patient was interviewed only once, telephone clarification was later sought if needed. Saunders et al (2003) declare that interviews are useful in gathering valid and reliable data that is relevant to the research question and objectives.

In semi-structured interviews, open-ended questions were used to collect patient information and pre-determined themes were covered. Questions varied from interview to interview. Some questions were omitted given the specific context and relation to the research. The order of questions also varied depending on the flow of conversation and additional questions were used to explore or prompt answers to gain better in-sight. Open-ended questions were used to encourage discussion and highlight specific issues under investigation. Appendix B provides the interview format used for the semi-structured interviews. Patient responses and discussions were recorded by note taking and tape-recording.

The recommendations made by Leedy & Ormrod (2005) for interviewing were closely followed and included ensuring that a suitable location was used for the collection of data, written permission was obtained (informed consent), rapport was established and maintained, and the focus of questions remained on the actual rather than on the hypothetical or abstract. Reponses were recorded and translated verbatim and leading was avoided.

3.6.3 Triangulation

Self-reporting in both the instrument and qualitative interviews posed a risk of social desirability responses. Historical review of the patient's chart assisted to confirm self-reported information. Interviews were conducted with three PHRU staff to validate interview findings.

3.7 Data Analysis

This study incorporated the analysis of data collected in two phases. In phase one, the existing CCS database was descriptively analysed. In phase two, 21 patients were purposively selected for qualitative interviews.

3.7.1 Phase One – Descriptive Analysis of Existing Database

In addressing the first sub problem, *the socioeconomic changes seen on commencement of antiretroviral treatment in a eighteen-month period*, phase one of the research entailed looking at patient data in the existing database to identify suggestive data trends.

The data collected in the CCS programmes as per the CRF reflects pre-test (baseline data with no ART) and post-test data collected with a time point for the intervention (ART). The research utilised descriptive statistics for this group of patients. There is no comparative control group. Babbie & Mouton (2001) state that descriptive statistics is a medium for describing data in manageable forms. Leedy & Ormrod (2005) add that descriptive statistics summarise the general nature of the data obtained.

For the analysis, baseline visit was counted as the visit before antiretroviral treatment was started and the most recent visit used as comparative data. The difference in data for the same variables for the same patients (paired data) in the sample over time was analysed. Data collected at patient visits for the 249 patients in the selected sample was sorted into recent visit data and baseline date (visit before the start of ART). For each patient the difference in this paired data was analysed (recent visit data – baseline visit data).

Each patient was counted only once and grouped based on the length of time they have been on antiretroviral treatment. The most recent visit to the clinic (last data collected) was used to calculate the length of time on treatment (Most recent visit date – Date ART started = time on ART in days).

Patients were assigned to groups if they had been on ART for ≥ 3 months (≥ 90 days), ≥ 6 months (≥ 180 days), ≥ 9 months (≥ 270 days), ≥ 12 months (≥ 360 days), ≥15 months (≥ 450 days), and ≥ 18 months (≥ 540 days).

The final patient sample analysed in phase one is depicted below:

Baseline Data	Follow Up Data	Follow Up Data (BASELINE FOR ANALYSIS)	ART Started	Follow Up Data ≥ 3 months (≥ 90 days)	Follow Up Data ≥ 6 months (≥ 180 days)	Follow Up Data ≥ 9 months (≥ 270 days)	Follow Up Data ≥ 12 months (≥ 360 days)	Follow Up Data ≥ 15 months (≥ 450 days)	Follow Up Data ≥ 18 months (≥ 540 days)
n = 3000			n = 642	n = 249					
				n = 45	n = 29	n = 42	n = 76	n = 43	n = 14

Baseline data for the sample was collected in the period from 03 July 2003 to 18 October 2005 (27 months). The paired data for the sample was collected with most recent visit data for the sample ranging from 26 July 2004 to 03 May 2006 (21 months). Antiretroviral treatment start dates ranged from 02 Feb 2004 to 28 November 2005.

The demographic and socioeconomic profile of the sample was characterised using descriptive statistics. The change in variables entailed descriptive analysis including the use of modes, medians, and means of variables.

3.7.2 Phase Two - Qualitative Analysis

The second sub problem: *how do these changes* (phase one findings) *affect the ability of individuals to participate in economic activity,* was addressed in phase two*.* Phase one analysis was complemented by qualitative analysis of 21 patient case studies. The final interview sample was selected from the PTAP programme in Soweto and is depicted below:

Total Patient Sample	Patients on ART ≥15 months	Patients on ART ≥ 18 months	Patients on ART ≥ 21 months	Patients on ART ≥ 24 months
n = 21	n = 5	n = 5	n =8	n = 3

Due to the lag time between the most recent visit information of the patients in the database and the actual date of the interviews, the sample of patients interviewed is not evenly spread across the time periods. Patients selected purposively for interviews based on phase one analysis are reflected above in the appropriate groups.

Meyers (1997) states that semiotics may be used as a tool for qualitative data analysis and is primarily concerned with the meaning of signs and symbols in language. Words can be assigned to primary conceptual categories, and the importance of an idea is revealed in the frequency with which it appears in the text. One form of semiotics is "content analysis" where structures and patterned regularities in the text are searched for and inferences are made based on these regularities. Another form of semiotics is "conversation analysis" where it is assumed that the meanings are shaped in the context of the conversation. This research combined both methods in the analysis of the gathered data in phase two.

Data from interviews was classified into meaningful categories. The categories were derived from the data itself (themes emerging in the responses) and the theory reviewed in the literature. These categories were used to label the data and rearrange the data so that it was meaningfully

analysed. A summary of the key issues was then tabulated. Additional information about the context and content of the interview and observation was also recorded. This was used to supplement the written up transcripts.

3.8 Reliability

Robson (2002) identifies four threats to reliability that researchers should be aware of (Saunders et al, 2003:101). These include the participant error, participant bias, the observer error and the observer bias.

The data collection utilised standardised CRFs and training to all staff has been provided for patient interviews. However some information required self-report from the patients. Leedy & Ormrod (2005) caution that interviewee responses on a rating scale may be influenced by their interpretations, prejudices, and memory lapses introducing a bias which may lead to imperfect validity.

In qualitative interviews the primary concern is of bias (both interviewer and interviewee). To address the concerns of reliability (and help overcome bias), the following measures by Saunders et al (2003) in undertaking qualitative research were adopted:

- The interviewer was prepared and ready for the interview and knowledgeable about the subject matter and the situational context thereby establishing appropriate credibility.
- The interviewee's confidence was gained by providing information about the research when the informed consent was discussed and this reduced the interviewees' uncertainties.
- Questions were phrased clearly and in a neutral tone.
- The use of open-end questions assisted in avoiding bias and leading questions were avoided. Long questions or those made up of more than two questions were avoided.
- The interviewer and interpreter demonstrated attentive listening skills and explored and probed explanations and meanings.

- Adequate time was allowed for interviewees to develop their responses.
- Understanding was tested by summarising the information provided thereby preventing incomplete interpretation.
- The collected information was transcribed soon after the interview.
- Sensitivity to cultural differences and interpreted responses were displayed.

These techniques in interviewing helped reduce bias and increased the reliability of the information collected. In interpretation of the data, responses were structured by using theories uncovered in the literature review to categorise responses into central themes. This avoided false assumptions in the interpretation.

3.9 Validity

Leedy & Ormrod (2005) state that validity of research is established if the findings are really what they appear to be. Saunders et al (2003) cite Robson (2002) in identifying six threats to validity that researchers should be aware of. These include history, testing, instrumentation, mortality, maturation, and ambiguity about causal direction.

Internal validity of research is the extent to which its design and the data it yields enables the researcher to draw accurate conclusions about the cause-and-effect and other relationships within the data. To ensure internal validity precautions can be taken to eliminate other possible explanations for the results we observe (Leedy & Ormrod, 2005: 97).

The research drew conclusions that are warranted from the data collected. Internal validity was established by using multiple sources of data. Results from descriptive analysis in phase one lead to in-depth investigation of key findings. Patient interviews followed. Review of the patient's records assisted in validating the patient's self-reported information. Interviews with three staff members at PHRU followed patient interviews to confirm staff experience in

working with patients who have commenced ART. Interview transcripts were coded exclusively by the investigator and uniformity in technique was maintained.

In addition, Tellis (1997) cites Yin (1994) in establishing validity in case studies by establishing a chain of evidence and the research followed these four principles in the analysis:

- Showing that the analysis relied on all the relevant evidence
- Including all major rival interpretations in the analysis
- Addressing the most significant aspect of the case studies
- Using the prior expert knowledge to further the analysis.

Leedy & Ormrod (2005) state that when data is standardised, admitting only those that comply with the criteria, the research effort can be controlled and the researcher can conclude with greater certainty what appears to be true. Therefore to ensure the integrity of the research, we must set forth beforehand precisely what standards the data must meet. Ethics-approved protocols that stipulate the entry criteria for patients into both CCS and PTAP programmes have been established at the PHRU. Approval for this research protocol was also obtained from the ethics committee.

3.10 Generalisability (External Validity)

Leedy & Ormrod (2005) describe external validity of research as the extent to which a study's results apply to situations beyond the study itself. To what extent can the conclusions drawn be generalised to other contexts?

This research will meet external validity in the extent to which it can be generalised to other HIV positive patients on antiretroviral treatment. This poses the question whether the findings can be equally applicable to other settings. The real-life setting enhances the external validity of the research. Given the number of HIV infected people in South Africa, the short-term impact of ART would be of interest to many corporate companies, programme

directors, researchers, households and the community at large. The research will also be able to direct further research.

Marshall and Rossman (1999) are cited in Saunders et al (2003), as suggesting that the ability to relate findings from a case based research to existing theory will demonstrate the results to have broader significance. Therefore the researcher in using the inductive approach believes that the research from the case studies will be theoretically generalisable.

Given the socioeconomic profile of the patient population in South Africa, the results may not be generalisable to HIV positive patients globally. However, stakeholders in developing countries may find limited benefit from the research on the socioeconomic effect of ART on HIV positive individuals. Other urban townships similar to Soweto may benefit from the findings of this research.

4 PRESENTATION AND INTERPRETATION OF RESULTS

4.1 Introduction

This research investigates the socioeconomic effect of antiretroviral treatment (ART) in HIV positive patients attending the Perinatal HIV Research Unit (PHRU) clinics in Soweto and Acornhoek in South Africa. This research was addressed primarily through two sub problems:

a. What socioeconomic changes are seen on commencement of antiretroviral treatment in an eighteen-month period?
    i. *How does personal/household income change over time?*
    ii. *What is the impact at the household level?*
    iii. *What change in employment, education and housing can be seen over time?*
    iv. *What is the effect on the patient's quality of life?*
b. How do these changes affect the ability of individuals to participate in economic activity?
    i. *How has commencing ART led to these changes directly or indirectly?*

This chapter begins with background information on antiretroviral treatment and social assistance, followed by a review of the time frames for phase one and phase two of the study. A brief demographic profile of the research sample is then given. The research results and corresponding interpretation are presented, followed by concluding remarks.

4.2 Background

4.2.1 Antiretroviral Treatment

The HIV virus attacks and slowly destroys the immune system by attaching itself to and destroying CD4 cells in the body. The CD4 helper cells are critical in the regulation and control of the immune response and serve as the body's defence system (Evian: 2000).

The purpose of antiretroviral treatment is to achieve HIV viral suppression and reduce the level of HIV to as low as possible which results in less immune damage. The onset of AIDS is delayed by reducing a decline in the health status of individuals. Triple therapy (a combination of three drugs) is recommended and treatment is ongoing and life-long. Unwanted and often unpleasant side effects from the drugs are possible. HIV may develop resistance to antiretroviral drugs and strict adherence to treatment is critical. Poor compliance and adherence to therapy and sub-optimal viral suppression may lead to drug resistance (Evian 2000).

Measuring the CD4 cell count is the best indicator of immune deficiency in HIV disease and is commonly used to monitor the immune status of an individual (Evian 2000:26). Another important marker in individuals infected with HIV is the viral load. The HIV viral load refers to the level of HIV virus in the blood stream and is the best indicator of the development of HIV disease (Evian 2000:27). The normal values for CD4 counts are between 800 and 1050 cells/mm^3 (Barnett & Gallant, 2004:18).

According to the National Antiretroviral Treatment Guidelines published by the Department of Health (2004), the primary goal of antiretroviral therapy is to decrease HIV related morbidity and mortality. Antiretroviral treatment is indicated for patients with a CD4 count < 200 cell/mm^3 irrespective of WHO stage or for patients with WHO stage IV disease irrespective of CD4 count. In addition, patients should be ready and willing to start therapy and understand the critical importance of adherence (Barnett & Gallant, 2004: 49).

When antiretroviral treatment is initiated, the concentration of HIV (measured by the viral load) falls rapidly. HIV viral loads can be reduced to below the level of detection within three to four months. If ART is stopped, HIV replication resumes and the viral load quickly reverts to levels prior to ART. In the absence of ART, the circulating HIV virus progressively weakens the immune system and is reflected in a decline in the CD4 cell count (Cleary et al, 2004:5). The CD4 count typically increases ≥ 50 cells/mm^3 at four to eight weeks after viral suppression with ART and then increases an additional 50-

100 cells/mm^3 per year thereafter. The CD4 count usually declines rapidly, up to 100-150 cells/mm^3 in three to four months when treatment is terminated (Barnett & Gallant, 2004:18).

Patients with advanced HIV disease, particularly those with a CD4 count of less than 50 cells/mm^3, may become ill with an immune reconstitution illness during the first few weeks of ART. Immune reconstitution illnesses occur when improving immune function unmasks a previously occult opportunistic infection. An immune reconstitution illness does not indicate drug failure or classified as an adverse effect (Department of Health, 2004: 11).

Side effects from antiretroviral treatment include nausea, vomiting, diarrhea, abdominal pain, skin rashes, lactic acidosis, lipodystrophy, hyperlipidaemia, anaemia, neutropenia, hepatitis, pancreatitis, and peripheral neuropathy (Department of Health, 2004). Side effects vary by drug and drug class and can begin as early as a few days after starting treatment. Short term adverse effects can start at a few weeks (two to six) after treatment initiation while long term effects can start as early as a few weeks after treatment and as late as five to 18 months after ART (Rudorf & Krikorian, 2005: 260).

The Department of Health (2004) recommends that the clinical and laboratory monitoring of patients include scheduled visits to see doctors and nurses, monthly collection of medication and safety, CD4 and viral load blood tests. Drug tolerance, adverse events (side effects) and adherence should be monitored regularly.

The cost of antiretroviral drugs has declined in recent years. At the PHRU, the cost for treatment of patients on first line therapy is under R400 a month. The PHRU Treatment Access Programme (PTAP) is funded by the United States Government's President's Emergency Plan for AIDS Relief (PEPFAR) and includes the provision of antiretroviral treatment.

4.2.2 Social Assistance

The Department of Social Development in South Africa provides social assistance to indigent people most in need of financial support. The vision of social security is to facilitate the protection, development and empowerment of human capacity (Department of Social Development, 2006).

The Department of Social Development (2006) distributes six types of grants that are subdivided into two groups: social grants and children's grants. Social grants include old age grants, disability grants and war veterans' grants. In order to qualify for a disability grant the applicant should be a South African citizen and resident and be at least 18 years of age. The applicant must be unable to enter the labour market due to the degree of the disability. The period of the disability for all work must be either permanent or temporary (for at least six months but not more than 12 months). The applicant must not refuse to undergo treatment unless it is life threatening. The applicant's spouse must comply with a means test and the applicant must not be maintained or cared for in a State Institution. If the applicant is married, annual income should be less than R37 512 and if unmarried, it should be less than R20 232 per annum. The applicant must not be receiving another social grant (http://www.sassa.gov.za).

HIV positive individuals may qualify to receive a disability grant on a temporary basis subject to meeting both the criteria above and a medical assessment. Re-application for a grant is possible if individuals are still not in good health and unable to work after a twelve month period. Before April 2006, a CD4 cell count below 200 cell/mm^3 was one of the factors used to assess the degree of disability and ability to work. An increase in CD4 count above 200 cell/mm^3 could have lead to the disability grant being revoked. According to the Department of Social Development, after April 2006, CD4 counts are no longer utilised as the primary indicator for determining eligibility of temporary disability grants. The revised guidelines for the disbursement of temporary grants are unpublished at present but are due to be released from

the Department of Social Development in the near future (N. De Wett, personal communication, 8 September 2006).

Children's Grants offered by the Department of Social Development (2006) include foster child grants; care dependency grants and child support grants. A child support grant may be awarded to a primary care giver if both are South African citizens and residents. The child must be under the age of 14 years and the primary care giver cannot apply for more than six children. The spouse of the applicant must also comply with means tests (Department of Social Development, 2006).

With the recent availability of ART, the subject matter of temporary disability grants for HIV positive individuals is being widely debated. An improvement in health subsequent to ART disqualifies individuals for the temporary disability grant leaving some individuals and households with no other source of income. This raises a grave concern given the high unemployment rate and poverty levels in South Africa.

4.3 Phase One

Baseline in phase one was defined as the last clinic visit before the patient commenced antiretroviral treatment. Baseline data for the sample was collected from 03 July 2003 to 18 October 2005 (27 months). The paired data for the sample was collected with recent visit data for the sample spanning from 26 July 2004 to 03 May 2006 (21 months). Patients commenced ART from 02 February 2004 to 28 November 2005. The total number of patients in the database analysed was 249. Thirty-six patients were seen at the Acornhoek clinic and 213 seen at the Soweto clinic.

4.4 Phase Two

Semi-structured qualitative interviews were conducted with 21 patients attending the PHRU clinic in Soweto. The PHRU social worker, two primary health care nurses and a medical officer of the PTAP programme were also

interviewed. Their experiences with patients were noted and served to validate self-reported patient responses. Interviews were conducted in six days from 31st July 2006 to 7th August 2006. Patients' charts were also reviewed during this period. Telephonic clarification was sought from selected patients on 10th, 11th of August 2006, and 7th of September 2006.

4.5 Demographic and Socioeconomic Profile of Patients at Baseline

The database analysed in phase one had a sample of 249 patients who had commenced antiretroviral treatment. The average age of the sample was 36 years. Seventy nine percent of the sample was female and 21% male. Ninety nine percent of the sample was Black/African. In reporting marital status, 17% were married (legally or traditionally), 60% were never married, seven percent were divorced, and five percent were separated. A further six percent were living together but not married. There were no reports of same sex partners.

Six percent of the sample reported education of tertiary level with four percent reported having no formal education at all. The remaining patients in the sample reported primary and high school education with the average highest school grade of eight.

The average household size of patients was reported to be five with an average of three rooms in the house. Eighty one percent of the patients reported that they or family owned or rented a brick home in which they lived, while 18% reported living in a shack in an informal settlement or in a backyard.

At baseline, the patients in the sample were largely unemployed with 80% reporting being without employment. Nineteen percent of the patients in the sample were employed (self or salaried or part-time/informally) and one percent of patients were students.

This sample represents a predominantly female, heterosexual, economically active age group of African individuals, who are for the most part unemployed.

This profile is consistent with current literature on population groups with high HIV prevalence rates, who share a disproportionate burden of the socioeconomic impact of the epidemic at both individual and household level in South Africa.

4.6 Results and Interpretation

4.6.1 Change in Income

The change in both personal and household income were analysed in phase one. In phase two, qualitative interviews were conducted to assist in the interpretation of phase one findings.

In phase one, the change in income was analysed by reviewing the personal and household income at baseline and then at the most recent visit. The change in mean income for each group of patients is summarised in table 1. The average period between baseline data and most recent visit data collection was 447 days (approximately 15 months).

The mean personal income for the sample was R598 at baseline and R907 at the most recent visit. The change in personal income over the period was R308, a 52% increase from the mean baseline income. In comparison, the mean household income at baseline was R1308 and R1438 at the most recent visit, with a mean change of R130 reflecting a 10% increase from the baseline mean.

All groups of patients consistently reflect an increase in mean personal income. The largest change in mean personal income of 98% over baseline is noted for the group of patients on ART ≥15 months. In contrast, the mean change in household income varies across patient groups. Patients in the group on ART ≥12 months exclusively display a mean decrease in household income (- R55). Possible explanations for these changes were further explored in phase two patient interviews.

Table 1: Phase one analysis: Mean personal and household income

		Total Patient Sample	Patients on ART ≥ 3 months	Patients on ART ≥ 6 months	Patients on ART ≥ 9 months	Patients on ART ≥ 12 months	Patients on ART ≥15 months	Patients on ART ≥ 18 months
		n = 249	n = 45	n = 29	n = 42	n = 76	n = 43	n = 14
Personal Income	Mean Income at Baseline visit (ZAR)	598	469	551	567	617	680	852
	Mean Income at Most Recent visit (ZAR)	907	648	721	889	843	1349	1163
	Change in Mean Income (ZAR)	308	178	170	322	226	669	311
	Change in Mean Income as percentage of Baseline Income	***52%***	***38%***	***31%***	***57%***	***37%***	***98%***	***36%***
Household Income	Mean Income at Baseline visit (ZAR)	1308	1141	1184	1175	1453	1371	1526
	Mean Income at Most Recent visit (ZAR)	1438	1238	1209	356	1398	1779	1973
	Change in Mean Income (ZAR)	130	97	24	181	-55	408	447
	Change in Mean Income as percentage of Baseline Income	***10%***	***9%***	***2%***	***15%***	***-4%***	***30%***	***29%***

The increase in mean personal income is substantially greater than that in household income. This is suggestive of extraneous factors that require consideration in exploring change at the household level. Some of these changes are explained in section 4.6.2. However, this does suggest that greater impact on an individual level is experienced.

The overall changes in means for both personal and household income (R308 and R130 respectively) were positive indicating an increase in income. In addition, the majority of the patients (72%) in the sample displayed an increase in personal income with a smaller proportion of patients (63%) reflecting an increase in household income. Given that 80% of the sample was unemployed at baseline, patient interviews investigated possible reasons for these changes.

In phase two, interview findings indicated that personal income increased as a result of both employment (formal and informal) and social grants. Increase in personal income was reported because of annual increases in social grants and newly awarded child support grant(s). Patients receiving grants are addressed further in section 4.6.1.1.

Patients reporting an increase in income due to employment attributed this to working extra hours, to informal sales, and securing new employment. These patients were on ART for 18 months or greater.

Patients expressed improved health after commencing ART and discussed improved income in this context. One patient responded that her income was not the same as it was prior to starting treatment, stating that, *"I now work extra hours because I feel better."* A second patient reported an increase in income *"because I found a job"*. This patient reported an increase of approximately R 2 400 a month. A third patient who engages in contract work in the construction sector reports that his life improved after starting treatment because "*I can now work… I'm feeling very strong to do that job*". He also reports that his income varies depending on the *"building"* jobs he gets but states, *"I can now get more money than before".*

It is evident that improved well being following the commencement of ART contributed directly to an increase in income for select patients thereby increasing their ability to participate in economic activity. This suggests a possible reversal of the economic impact of HIV related ill–health at an individual level.

The literature addressing the impact of HIV refers regularly to increased morbidity (Barnett & Whiteside, 2002), leading to decreased productivity (Desmond et al, 2000) and absenteeism from work (Smit et al, 2001), which reduces earnings (UNAIDS, GBC & PWBLF, 2000). Since the literature on the impact of ART on income is extremely limited, the empirical evidence clearly identifies the need for further investigation into the quantifiable impact of ART on individual income levels and the duration any benefits can be

sustained. Exploration into the feasibility of reversing the documented effects of HIV on both a microeconomic (as suggested in this research) and macroeconomic level will serve to inform multiple stakeholders of possible future policies and interventions.

The qualitative interviews suggested that household income increased directly in relation to personal income. Reasons as already cited by patients for personal income increases include new employment and annual increases in social grants.

One patient attributed an increase in household income to new employment. She is now works full time from being unemployed for five years and reports that household income has increased concurrently with her personal income because *"I'm helping at home, my sister and my mother is still working and its only three of us".*

There is not enough empirical evidence to suggest that increases in household income can be directly associated with commencement of ART. For select patients an indirect association exists, as an increase in personal income led to the increase of household income.

Phase two interviews facilitated understanding the decrease in income found in phase one analysis. Patients reported that personal income had decreased due to job loss (both formal & informal) and the loss of grants (discussed further in section 4.6.1.1). Patients reporting this were on ART between 16 and 24 months. In addition, patients reporting a decrease in household income explained that this was due to either the patient or others in the household losing a job. Patients also reported that household income decreased due to the loss of grants.

Patients confirm that cessation of both formal and informal employment was directly due to ill health. One patient reports that her income has decreased because, *"I was doing temporary job. Now I am not working, I am still looking for the job."* She has been on ART for 16 months and describes in her

interview that she was sick for two months before starting treatment and was admitted to hospital. She is supported by her husband and receives a child support grant.

Patients report that formal employment was terminated by way of voluntary resignation. A patient that was employed part time in a factory, cleaning embroidery previously is currently formally unemployed. Her personal income has decreased. She receives a social grant and supplements her income by selling Tupperware. She explained that she decided to resign from her job before her boss was complaining that she was *"always"* sick and she only earned R800 so she decided to resign for the sake of her health. She has been on treatment for approximately two years and reports that she is actively looking for work at present.

Another patient reported that her income decreased by about R 1500 because *"I lost my job when I started to become sick from ART's. After using ART's I became sick and I couldn't walk so that is how I lost my job."* The patient reports that she resigned from her position, as she was unable to reach her performance targets. She receives a social grant and states that she has been searching for employment for two years. She has been on ART for 22 months and has documented peripheral neuropathy (a side effect linked to certain treatment drugs).

The ability to work informally was also compromised. A patient on treatment for 18 months sold clothing informally and explains about her decreased income, *"I became sick and I stopped selling."* She adds that when she became ill she was unable to collect money that was owed to her.

This finding concurs with current literature that HIV increases morbidity (Barnett & Whiteside, 2002) affecting people in their most productive years through the reduced earnings due to illness (UNAIDS, GBC & PWBLF, 2000). While reports of return to work for those employed after the commencement of ART (Brink, 2003) are available, it is apparent that return to well being may not reverse the impact of HIV on income for all patients. This necessitates

further discussion on the availability of employment opportunities and is addressed in detail in section 4.6.3. The ability of patients to actively seek employment (and therefore participate in economic activity) despite this decline in personal income is evident in patient case studies.

Patient testimonies reveal that decrease in household income was due to job loss or the loss of social assistance. One patient indicated that the death of a grandmother meant that the household lost a grant and explains about her household income, *"It decreased because my mother lost her job, my grandmother died"* and added further that her grandmother used to *"help with grant money".* Another patient who works informally, lost her grant and reports that household income has decreased, *"because we only live on my grandmother's grant and mine was stopped".*

One patient cited unemployment of another household member as the cause of decrease in household income. This patient who is employed reported a decrease in household income because, *"my sister and I were bringing more money at home but now because she is retrenched we have to rely on one income".* She reported that her expenses have increased as she supports her two children and now financially assists her sister who lost her job. This highlights some of the extraneous factors that were uncontrolled for in the design of this study.

Multiple factors require consideration when investigating income of households affected by HIV and changes in income levels subsequent to ART. Loss of both employment and social assistance grants are reasons cited by patients for decline in household income. Investigation into job loss at household level extends beyond the scope of this research and requires examination by way of a controlled household study.

In phase one, it was noted that 16% of the patients had no change in personal income and 10% of patients had no change in household income. In phase two, of those patients that reported no change in personal income, some were receiving grants and reported no change therein. One patient explained that

although she had lost her job *"because I was sick and I couldn't work as a sewer* [machinist] *anymore'* she was now receiving a grant and therefore her income remained unchanged.

4.6.1.1 Patients Receiving Grants

While analysing the income in phase one, it became clear that change in income could not be addressed without accounting for those patients dependent on social grants. It became imperative to isolate changes in grants to avoid misinterpretation of the change in income for the entire sample and seeking possible reasons to explain these changes. The change in grant amounts available from the Department of Social Development (2006) is summarised below:

Table 2: Social and child grant awards from 2003 to 2006

	Old Age Pension Grant	Disability Grant	Care Dependency Grant	Child Support Grant
2003	R 700	R 700	R 700	R 150
2004	R 740	R 740	R 740	R170
2005	R 780	R 780	R 780	R180
2006	R 820	R 820	R 820	R190
Year on Year Increase	***R40***	***R40***	***R40***	***R20 then R10***

Source: Tsotetsi, M., personal communication, 14 August 2006

In phase one, 211 patients representing 85% of the sample reported being on a grant at some point. Of the 211 patients on grants the majority were on disability grants and a small proportion received child grants (28 patients).

Seventy-nine percent of the patients receiving a grant/s at some point had an increase in personal income after commencing ART. The average increase in personal income was R484 with a mode of R780. This mode represents twenty one percent of the patients with an increase of R780 in income, which may be indicative of being awarded a grant for the first time. A further 19% of patients exhibited an increase of R40, which is suggestive of patients who are

already receiving a grant reporting an increase equating to the annual increase in the amount of the grant. An additional three percent of patients showed an increase of R10, which could be attributed to the annual increase in the amount of a child support grant. Eight patients reported losing grants and decrease in income levels could be related to this loss.

In phase two, patient interviews supported this interpretation. One patient who reported an increase in personal income explained that the increase was due to an increase in the amount of the grant from R740 to R820 and another reported an increase of R190 because she now received a child support grant.

One patient on ART for 22 months reported a decrease in income of R900. The patient lost a grant of R740 and additional income from part-time work. Another patient that reported a decrease in income lost a grant she had been receiving for 12 months because her CD4 count was above 300 cells/mm^3. A third patient on ART for 21 months reported a decrease in income equating to the amount of the grant she had been receiving. She lost her grant and commented that, "*…the doctors from social services decide to close it* [grant] *because they think that I'm still capable of work".*

In phase one, 91 patients reported household income from grants. Patients reported receiving income from old age pension (46 patients) disability grants (17 patients) and child support grants (45 patients). Some reported receiving more than one kind of grant. Of these 91 patients, 58% showed an increase in household income (mean of R478 and mode of R50), and 34% a decrease in household income (mean of - R1434 and mode of –R1440). The mean decrease in household income is notably high and suggests that improvement in income at the household level remains challenging for this sample.

In phase two, some patients confirmed that households received two grants, one from the patient, and another from other family members (mother, child, grandmother). One patient that reported an increase in household income attributed this directly to an increase in the grant she was receiving. Other

patients indicated that household income decreased as a result of losing a grant.

Two of the primary health care nurses working in the PTAP programme at the PHRU stated that a few patients had withdrawn from treatment in order to keep their grants especially when no one else was working in the household. The social worker at the PHRU confirms further that some family members of patients have reported that patients feel despondent about losing their only source of income (grant) and stop treatment in an attempt to cause a decrease in the CD4 count to re-qualify for a temporary disability grant. The implication of stopping treatment is grave as it contributes to the development of treatment resistance.

This concern has also been raised by Hardy & Richter (2005) who reported that the AIDS Law Project was approached by staff of a public hospital in 2004, who expressed concern that the fear of losing their disability grants may encourage HIV infected individuals to refuse ART or not take the treatment correctly in order to keep their disability grants. Patients appeared to be forced to choose between receiving their disability grant and accessing life-saving medication.

It is also clear that the majority of the patients in this sample during the first 18 months after treatment utilised temporary disability grants as the primary means of income and sustenance, and is in keeping with literature findings reported by Naidu & Harris (2005) who found that significant portions of income from non-earned sources were evident in poorer households. This research indicated that changes in both personal and household income could be directly linked to single or multiple social grant(s).

In time, with improvement in health (clinical recovery from ART), the consequence of starting ART for these patients will involve loss of income when temporary grants are terminated. In the absence of additional sources of income, these patients are expected to be financially worse off.

The issue of temporary grants for HIV patients is thus widely debated at present. An improvement in health subsequent to ART disqualifies individuals for temporary disability grants leaving some individuals and households with no income. Nattrass (2004b) argues that the disability grant serves as an important income lifeline for poor AIDS-affected households to the extent that lower household income translates into lower food expenditure, and may adversely affect the nutritional status of people on ART.

The social worker interviewed at the PHRU stated that at times social grants were seen as the solution to poverty (not education or employment). She stated that a small number of patients view the diagnosis of HIV as a blessing as it allows for access to social grants. This concern is shared by Nattrass (2004b) who raises the possibility of disability grants offering perverse incentive to individuals. Anecdotal evidence from the Western Cape, Eastern Cape and KwaZulu Natal was cited where individuals who tested HIV negative were reported becoming angry as they had hoped to qualify for a grant.

4.6.1.2 Conclusion

The overall increase in mean personal and household income for patients who have commenced ART is suggestive of a general improvement in the ability of individuals to participate in economic activity. The notable improvement in physical health and quality of life (further discussed in section 4.6.4) support the changes in income that are evident for patients on ART as early as three months. An average increase in income of 52% over baseline in a 15-month period on average exceeds annual inflationary increases and indicates the need for alternate explanations.

The prevailing themes that emerged in patient interviews regarding income were of employment status and social assistance grants. However, with 80% of the sample unemployed at baseline, and 85% on a grant at some point, the change in income is largely attributed to change in grant amounts, loss of exiting grants and receipt of new grants.

However, other reasons for changes in income cannot be discounted. Grants may also be supplemented by informal work. For those patients not on grants, testimonies indicate that changes in income at both personal and household level may be credited to changes in both formal and informal employment. These changes in income (either increases or decreases) were directly linked to employment and clearly credited to working extra hours, to informal sales, new employment and job losses. It is evident that household income changes directly in relation to personal income in some cases.

Patient statements in phase two provide empirical evidence that the ability to participate in economic activity is hindered by ill health. Antiretroviral treatment directly contributes toward patients' recovery to well being. Return to both formal and informal employment, with an increase in the capacity to seek employment (discussed further in section 4.6.3), and concurrent average increase in income suggests that patients post-ART may be able to recover from the economic impact of HIV. Patients indicate that commencement of ART has directly (at individual level) and indirectly (at household level) lead to the ability to participate in economic activity.

4.6.2 The Impact at Household Level

In addition to the results already presented on household income, this section aims to further explore the impact of commencing ART at the household level by including investigation into household size, change in household head and household expenditure.

4.6.2.1 Household Size and Head

In phase one, the average household size of patients was reported to be five with an average of three rooms in the house. At the most recent visit 116 patients reported a change in the household head. Additional information was not consistently recorded for these patients in the database. In patient interviews, some patients reported being the primary breadwinner. Others reported living with parents, siblings and children. This change in household heads and household size is widely documented in the current literature.

4.6.2.2 Household Income

In phase one, in addition to a mean change of R130 in household income, it was noted that the mean household income per capita at baseline was R303 with a corresponding mode of zero. This mode represented 11% (27 patients) of the sample. At the most recent visit, four of these 27 patients still reported household income of zero. Further investigation revealed that thirty patients reported non-work household income from gifts (23 patients from household members and seven from non-household members).

Clarification of this finding was sought in patient interviews where one patient reported an income of zero but survived on in-kind transfers. Her rent was paid directly by a non-family member and food was provided by a community based organisation. In households where patients were not working and/or receiving a grant, additional financial and non-financial support was provided mostly by family members (mother, boyfriend, grandmother, daughter, brother and cousin).

In phase one, 26 patients (10% of the sample) reported that someone in the household missed a meal at the baseline visit but not at the most recent visit. This decrease in the number of meals missed in the household indicates that some households have better access to food most recently. The average decrease in the meals missed was two meals. The majority of these patients displayed a concurrent increase in income with the few remaining patients reflecting no change in personal income. Only two patients exhibited a decline in household income. This decrease in meals missed in patient household implies that some households are accessing food directly or experiencing financial improvement as already indicted by the overall increase in mean household income.

In phase one, ten patients (four percent of the patient sample) reported that meals were missed in the household in the past week at the most recent visit but not at baseline. Half of these patients displayed a concomitant decrease in household income. This increase in the number of meals missed from baseline also implies that despite an average increase in household income, some patients were experiencing food shortage while on ART. This is confirmed by one unemployed patient in phase two, who lost her social grant and was dependent on a home based care agency for food supply. She commented that she could not afford the *"healthy food"* advocated in HIV programmes. Only one out of these ten patients in phase one analysis showed a decrease in personal income, implying that impact at the household level is subject to multiple variables and may not be significantly attributable to individual patients commencing ART.

Inadequate personal and household income compromises the availability of food for patients and their families. Although a higher proportion of patients reported that the number of meals missed in the household decreased over time, there were some reports of meals missed at recent visits supporting the literature findings that the decease in household income reduces food security (Desmond et al, 2000). However, the decrease in meals missed in some households suggests that the provision of ART could indirectly improve food security if income has improved.

4.6.2.3 Household Expenditure

Although spending patterns were not investigated in this study, some information regarding household expenditure was revealed in patient interviews. Increase in household expenditure were reported and ascribed to taking care of orphans, supporting children outside of the home and supporting other household & family members.

One unemployed patient receiving a grant explains that financial expenses in the household have increased because she resides with her nieces from a deceased cousin, who do not work. In addition, her sister died and she is taking care of her twin children. The patient added that one cousin in the household was employed. Another patient remarked, *"…before I started ARV's I was spending a lot of money on doctors".* Patients also report deaths in the household recently had affected disposable household income.

4.6.2.4 Support Structure

Almost all patients in qualitative interviews cited family members as providing necessary support to them. The evidence suggests that the patients' family provides critical financial and emotional support to patients. Whilst a few patients reported benefiting from treatment support groups, most patients relied on family members for support. One patient reported moving in with her mother when she was ill. Another patient explained that she received support from the shelter in which she lived soon after commencing ART.

A third patient who has been on ART for 17 months, explained that he was offered emotional support mostly from his mother. He adds that some of his friends provided support but "*not all of them. Some of them deserted me*." After his HIV status was disclosed, *"they thought I was leaving them, going to die. They are so surprised to see me improve from what I was"*. Other patients reiterated this theme of stigma and discrimination.

4.6.2.5 Conclusion

Patient testimonies indicate that the impact at household level on commencement with ART does not differ widely with literature on studies of households affected by HIV. Individual improvement in income and health can be directly linked to ART and therefore indirectly at the household level. Food security improved in some households but raises the concern about access to good nutrition as part of a comprehensive treatment programme. Family members provide the majority of patients with the necessary support structure through both HIV illness and recovery.

These findings support the current literature on the effects of HIV at household level but lacks substantial empirical evidence to suggest that the commencement of ART has lead to considerable change at the household level. Multiple factors that affect the household as cited by Barnett & Whiteside (2002) in the literature were not the primary focus of this research and should be addressed in further research.

4.6.3 Change in Employment, Education and Housing

The change in employment status, education and housing was recorded in the database in phase one. These changes if noted were probed in phase two interviews

4.6.3.1 Change in Employment

At baseline in phase one the occupational status of 244 of the patients in the sample was recorded as follows: two percent were self-employed; one percent were students; 15% were employed (salaried workers); two percent were employed part-time or on temporary basis; and 80% were unemployed.

In phase one, nine patients (about four percent of total sample) reported a change in employment. Of the nine patients reporting a change in employment, eight were unemployed at baseline. Six of these eight patients with a reported change in employment in phase one were interviewed in phase two. Due to the lag time between the most recent data in the database and the actual date of the interviews, discussions regarding employment revealed that changes in employment were not consistent with phase one findings. Patients had subsequent changes in employment, those with documented change to employment status reporting an additional change. Also uncovered in patient interviews, was the under-reporting of employment. Some patients revealed that they were employed part time or engaged in informal work at baseline but had reported being unemployed.

Unemployed at baseline, presently employed

In phase one, eight patients from the baseline of 195 unemployed patients reported being employed (reflecting four percent of total unemployed patients in the sample) at the most recent visit. Of those patients that commenced work, one was on ART ≥ 3 months; two were on ART ≥ 9 months days, one was on ART ≥ 12 months and four on ART ≥ 15 months. These changes were further explored in patient interviews.

In phase two, patients who were unemployed before commencing ART but employed at the time of the interview reported being both formally and informally employed. Informal employment was not generally deemed as "employment" by patients and was typically undertaken for financial support whilst patients are seeking formal employment.

One of the patients who reported finding employment commented, *"I wasn't getting any job at all, it was difficult to get it because I was doing everything I could, but with no luck".* This patient was on ART for 18 months and reports that she secured a full- time position at a deli and was assisted by her sister who works at the same place to secure employment. She reports in addition that she has been searching for a job for a total of five years and was *"sending CVs and asking friends and family to do that."* Her income has increased as a result of her securing employment. She confirms that she was not unemployed because she was sick and never required assistance prior to starting treatment. But she also notes that her life has improved after three months of starting treatment because *"I no longer fall sick".*

Another patient who was unemployed before starting ART has been looking for a job unsuccessfully and has taken up informal work to support herself financially after she lost a grant she had had been receiving for 12 months. She claims that she has been unable to secure employment because *"I cannot express myself in English and companies are looking for experience and I don't have it'.* She has been on treatment for 22 months and her grandmother assists her financially.

The ability to work is expressed by a patient who was employed part time prior to starting treatment and has been looking for formal employment for six years. She receives a grant and supplements her income by working informally selling Tupperware. This patient reported falling sick frequently prior to starting treatment and *"needed help with almost everything" and* states that *" I used to be sick, now I am strong and do things myself. I feel I can even work"* She noted changes and improvement in her well being three months after starting ART.

It is evident that improvement in well-being enabled patients to take up informal work in the absence of formal employment. Clearly improvement in health cannot directly result in formal employment given the scarcity of job opportunities in South Africa. However patient testimonies indicate that the commencement of ART has directly led to an improvement in health, which in turn has allowed for informal employment and restored ability to seek employment and ability to work. There is empirical evidence that these benefits are attributable to the commencement of ART, and in doing so restore the ability of patients to be economically active.

Employed at baseline, presently employed

In phase two, patients who had no change in employment status reported being both formally and informally employed. A decrease in absenteeism is noted after the commencement of ART. One patient who has been employed at the same job since before she commenced ART states that, *"since I started ARVs I haven't fallen sick or been admitted at hospital"* and reports that she utilises leave days or has money deducted for absenteeism because *"I have to be absent every month to come for medication and doctor's visits."*

Another patient reported that '*after I started drugs* [ART] *I stopped falling sick. I use to not go to work because of weakness… And now going to work has improved. Two to three months after taking drugs I saw changes."* This patient reported an increase in personal income commenting that, *"I now work extra hours because I feel better".* This patient also reported that he received support from his *"family, friends and at work ".*

The theme of improved well being is reinforced by other patients. One patient who was previously employed (before commencing ART) and lost his job when the company he was working for closed down. After searching for a job for one year, he is now employed again. He was able to secure this job through a friend who is the manager in the restaurant where he is now employed. He reports that he *"used to get sick for a very very long time but now I don't get sick like before".* He added that, "*… lately I am working. I am managing because at first I used to get tired but now I don't get tired*

anymore". Another patient stated, *"I have a friend… who was very sick but after I took her to commence treatment she is now ok and she* [has] *also gone back to work."*

Phase two findings indicate that patients on ART who are employed are able to remain employed and report a decline in illness, which reduces absenteeism. This is consistent with literature documented by Brink (2003), Love (2004) and Ellis & Terwin (2005). The ability to work extra hours lends support to the argument of increased productivity while one patient alludes to work providing a suitable support system. It is evident that ART leads directly to the ability to remain economically active for these patients. This finding is supported by Love (2004).

Employed at baseline, presently unemployed

In phase one, only one patient reported a change in employment from being employed. Because of the time lag between the phases, patient interviews revealed a total of six patients that were employed before starting ART who were unemployed at the time of the interview. Both formal and informal job losses and reasons for these losses were explored. Job losses were equally attributed to company closure and compromised health.

One patient lost her job as a machinist because *"the employers closed the company and went back to Tokyo"* and another stated, *"I used to work for* [a] *company that closed because of tax owing"*.

The subject of compromised health was the focus of many patient discussions. An unemployed patient who used to be informally employed stated, *"Right now I'm not working but I used to do the washing and ironing for other people but I became sick …"* She further stated that she has been receiving a grant, which she has now lost and has been unemployed for two years and *"searching through other people"* for work. Another patient who work informally selling clothing stated, *"I became sick and I stopped selling."*

A patient who was previously employed states that she stopped working because "*I got sick … then I found out that I was HIV positive and couldn't walk"*. She has been searching for a job for two years and currently depends on a grant for her income.

Another patient who was employed full time previously stated, *"After using ART I became sick from them and I couldn't walk so that is how I lost my job"*. She reports resigning from her post. The patient has been on ART for 22 months and has been searching for employment for two years. She is currently getting a grant and believes that ART improved her life and she would recommend ART to other HIV positive people as *"they also helped me a lot"*. She is currently looking for a job and believes that *"employers are looking for experiences and they think I have been out of employment for too long"*.

Compromised health cannot be exclusively held responsible for job losses. Labour market challenges also contribute to employment loss. It is clear that ill health from HIV has resulted in job loss for patients and improvement in health should therefore theoretically restore the ability of patients to work and be economically active. However patient testimonies indicate that in reality this is not the case, and securing employment remains challenging.

Unemployed at baseline, presently unemployed

In phase two, the majority of the unemployed patients reported that they are actively looking for work. Lack of education, skills and work experience are cited as reasons for not securing employment. Patients are of the opinion that "*there are no jobs out there*".

Patient testimonies suggest that although unemployed, patients have the ability to work and are actively looking for employment. A patient who has been on ART for 20 months commented, "*I was very sick … sometimes I had a running stomach and vomiting all the time after eating. In fact after* [a] *month* [of] *taking treatment I just saw a lot of changes in my life.* When asked if she had been working before commencing ART the patient responded, *"No, I*

wasn't working and even now I'm not working but I'm feeling good to work because I also applied for different jobs and if something comes up I'll definitely go for it". She has a standard 9 high school education and adds that, *"There are no jobs out there. I'm not getting any job, I do ask people or check other companies for help but they don't want people without experience and education."*

Of those patients that are not seeking employment, one explains that she is not looking for work because *"I'm tired of looking for job …I am getting too old and they are looking for young blood"*. She is 53 years old and receives a grant. She lives with her daughter who is the breadwinner in the house. Another patient who is not searching for work states that she is physically unable to work, and comments *" I can't walk with my feet because I am using four wheeled crutches"* and states that she is not looking for a job presently *"because of my condition"* and *"because there are no jobs out there"*.

Unemployed patients were asked why they thought they were unable to find work. Responses included reasons such as "*there are no jobs out there*". Lack of work experience, skills and education were cited as reasons for not securing employment. One patient who was previously formally employed lost her job when she got ill from HIV and has been looking for a job for two years commented that, *"I'm not getting the job because maybe I'm not well educated."* And then adds, *"to be honest there are no jobs out there because even those people who are well educated are not working".*

Another patient commented, *"I'm not skilled enough. I didn't get much education and companies are looking for skilled and experienced people,"* The patient reported an education level of Standard 9 at baseline. He adds that he has been searching for a job and *"I'm not choosy, anything is still okay … as long as I get some income"*. The issue of discrimination was raised by a patient who commented that, *"There are no jobs out there, because companies are discriminating whether it's a black person or uneducated, they still discriminate against women."*

The length of time patients were seeking employment varied with responses of one year, two years, and five years. Others responded that they had been searching for work "*for long*", since "*forever*" and "*all my life*".

It is clear that employment in South Africa is a challenge. With official unemployment rates of 28% in 2003, 26.2% in 2004 and 26.7% in 2005 (Statistics South Africa, 2005) job opportunities are scare. In addition, lack of education and skills cited in this research increase the likelihood of not securing employment. The ability to seek employment has clearly been linked to improved well being and directly ascribed to ART. The fact that those that are unemployed are actively looking for work and able to work, suggests that they have the ability to become economically active. This further suggests that they are not discouraged work-seekers.

According to the Labour Force Survey (2005) published by Statistics South Africa, unemployment rates among black African people in South Africa are higher than among other races by a large margin (31.5% for black Africans compared to 22.4%, 15.8% and 5.1% for Coloured, Indians and White races respectively). In addition, the report indicated that unemployment rates for women are substantially higher than for men. Since patients in this study are predominately female, black African with a corresponding high unemployment rate at baseline, the ability for this group of patients to secure employment is already severely compromised. The consequences of which are highlighted by Evian (2000) who states that high unemployment rates promote migrant work and forces women to sell sex thereby further promoting the spread of HIV.

The ability to compete equally in the employment market

When patients were asked whether they could compete equally with HIV negative people in the employment market, the majority of the responses were in the negative. Patients felt that they could not compete with HIV negative people in the employment market. Some patients commented that prospective employees might discriminate against HIV positive applicants based on either self-disclosure or physical appearance. One of these patients

commented, *"… it becomes routine that people look at you and decide that if you lost weight, or have skin problems you are HIV positive, even the interviewers themselves are that discriminating."*

Few patients reported that their HIV status did not affect their ability to compete in the job market. One patient stated that when seeking employment one's status should not be disclosed and the other patient remarked, *"…to get the job it does not mean you have to be HIV positive or negative because I think it's a luck to find a job. It won't make a difference because I am confident that if it happens that I do get a job it will be that I'm capable of doing it'.*

Concern about stigma and discrimination in the workplace is apparent in patients' responses. This indicates the need for workplace programmes to address these issues and for recruiting staff to be complaint with non-discriminatory conduct in the selection and interviewing process. The perception that HIV status reduces the likelihood of competing in the job market suggests that economic activity may be hindered if individuals are discouraged from seeking employment.

4.6.3.2 Change in Education

Phase one analysis revealed that six percent of the sample had tertiary level education and four percent had no formal education at all. Of those patients reporting primary and secondary school education (223 patients in total), the average highest school grade was eight with over 70% of the sample having attended grade seven or higher and 17% having attended 12th grade (matriculated).

Five patients (two percent of the total sample) reported a change in education level but no information on the actual change was recorded in the database. Of these five patients reporting a change in education, two patients reported at baseline that their highest school grade was three, and one patient each reported the highest school grades of eight, nine and ten. These patients did not report a concurrent change in employment. Four of these five patients had

a reported increase in personal income over the period averaging R1390. One patient had a reported decrease in personal income of R2696.

In patient interviews, no change in education level was reported. One patient reported that she would like to consider adult education but has no money for the fees. Her highest level of education was standard two. Another patient reported that he was saving money to go back to school. The patient's documented highest level of education was matric.

Patients have already cited lack of education as a key barrier to securing employment. The insignificant change in education is indicative of the lack of resources available to the patient population to improve education levels. For those solely dependent on grant income for sustenance, improving education may not be a priority.

4.6.3.3 Change in Housing

Analysis of the database in phase one showed that the average household size of patients was five with an average of three rooms in the house. Sixty eight percent of the patients interviewed reported that they or family owned a brick home in which they lived, 13% reported renting a brick home. Twelve percent reported living in a shack in an informal settlement while six percent reported living in a shack in a backyard. Only one percent reported living in a hut. In phase one, one patient reported a change in housing. No additional information was available in the database on what the change in housing was.

From patients' interviews, it is evident that change in housing is primarily driven by the need for assistance and support (financial, physical or emotional). It is evident that the family plays a critical role in the support structure for patients. The issues of discrimination in the household and disclosure were hinted at in interviews but not investigated further.

Of those patients reporting a change in housing during interviews, one patient reported getting his own place after getting employed and another stated that

she moved in with her mother when she got ill and needed help. A third patient reported that she went to a shelter when she started ART. The patient was living with her aunt previously, and was employed. She stopped working when she got sick and discovered that she was HIV positive. She states, *"I didn't want to talk to people, I even went to live in a shelter.* The Social Worker at the PHRU refers HIV patients to a shelter when they begin treatment and have no access to food.

4.6.3.4 Conclusion

In phase two interviews, it is evident that improved health facilitates an increased capacity to search for employment and enables patients to become employed and engage in informal work to generate income. Improved health is credited to ART and for that reason can directly lead to economic activity. This finding is supported by a small panel study conducted in Khayelitsha by Nattrass (2004b) who reported a significant rise in labour-force participation as a consequence of ART.

Unemployment may not be directly related to ill health and is primarily due to the inability to find suitable employment. However job loss (either formal or informal) could be a direct result of HIV illness. Patients indicating that voluntary resignation at the time of ill-health lead to job loss, indicate the critical need for education in the workplace on HIV policies and rights of HIV positive employees. Individuals should be discouraged from exiting the labour market and should utilise alternatives such as extended sick leave, unpaid leave or ill-health benefits. Given the high unemployment rates in South Africa, this will prevent individuals from having to re-enter the labour market on physical recovery.

For employed individuals, workplace interventions should focus on the early detection of HIV. This could aid in preventing ill health if immediate access into HIV care and treatment programmes is available. Workplace programmes should also work toward reducing stigma and discrimination in the workplace, which will further facilitate employees seeking assistance rather than

voluntarily resigning from employment. Current literature (UNAIDS et al, 2000; UNAIDS, 2002; Dickinson, 2003; ILO/UNAIDS/GHI, 2003; SABCOHA & BER, 2005; Ellis & Terwin, 2005, and UNAIDS, 2005) on workplace initiatives advocate inclusion of ART in workplace programmes and suggest that prevention, and education efforts be combined with testing and counselling efforts. While a decline in absenteeism from work due to ill episodes and hospitalisations is noted, the need to attend clinics for medical appointments and ART collection can continue to contribute to absenteeism or utilisation of leave.

Those that are unemployed are actively looking for work. The general perception is that employment opportunities are scarce and lack of experience, education and skills are barriers in securing formal employment. The majority of patients do not feel that they can compete with those who are HIV negative in the employment market. Although many of the patients reported an improved quality of life and equated their health to those of 'normal' people, concern of stigma and discrimination are clearly evident in some testimonies.

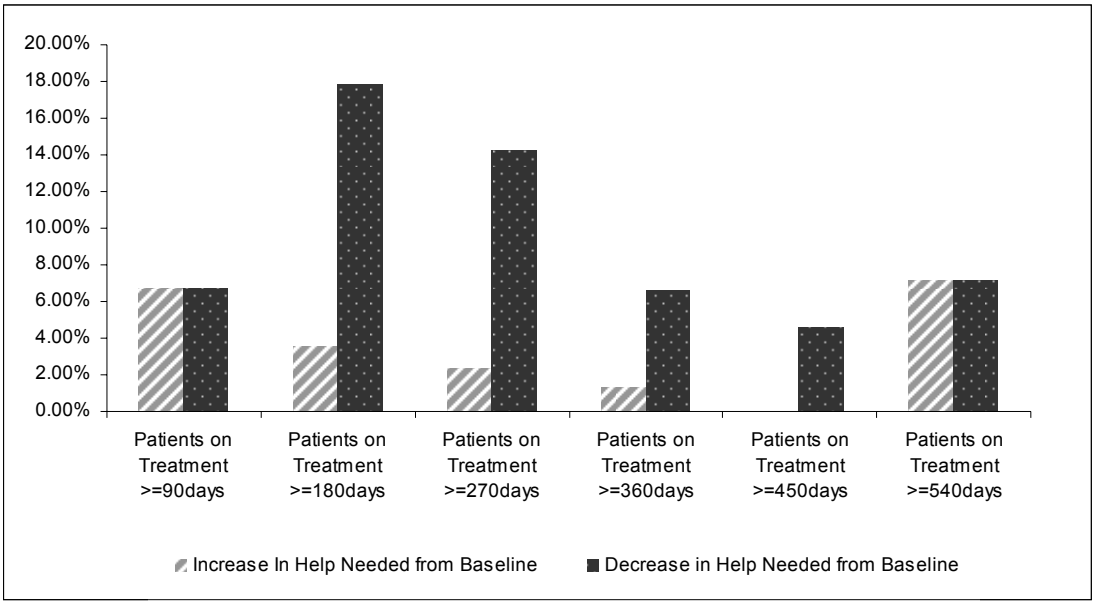
4.6.4 Effect on Quality of Life

In phase one, analysis of the database showed the change in the variable "help needed" and "number of hours" help was needed for patients who had commenced ART. In phase two, the level and need for assistance and reasons for noted changes were explored. The quality of life was also investigated in patient interviews.

4.6.4.1 Change in Assistance

In phase one, a total of 29 patients reported ever needing assistance with daily activities. Of those requiring assistance at some point, 24% reported needing more assistance than before starting ART and 76% reported needing less assistance than before commencing ART. The change in assistance for the different patient groups is depicted below in Figure 1.

Figure 1: Proportion of patients reporting change in assistance with daily activities



Increase in assistance

In phase one, seven patients (three percent of total patient sample) were noted needing help with daily activities at the most recent visit but not at

baseline (an increase in assistance). The average increase in the number of hours help was needed at most recent visits was 3.8 hours. The proportion of patients with an increase in assistance equals the proportion of patients with a decrease in assistance for the groups on treatment for ≥ 3 months and ≥ 18 months. It is also noted that the proportion of patients needing more assistance than at baseline decreases steadily as patients are longer on treatment.

Patients with advanced HIV disease are subject to the greater likelihood of side effects and toxicities (Evian 2000) and those commencing treatment with a very low CD4 count may experience Immune Reconstitution Syndrome (Department of Health, 2005) and could possibly not experience improvement in health within the first three to six months. This may compromise the patient's ability to complete daily activities. Patients could experience more episodes of "illness" because of this, and therefore need more help than previously.

Of those patients requiring assistance presently, one reported needing help infrequently but for the most part could "*do things for myself*" and noted after starting ART has been *"able to wash and clean the house and hang my washing outside. I am able to do that now".* Another patient indicated that she needed help at times as she "*still feels tired*".

Decrease in assistance

In phase one, a greater proportion of the sample showed a decline in needing help with daily activities from baseline. Twenty-two patients (nine percent of the sample) reported needing help at baseline but not at the most recent visit. The average decline in the number of hours that help was needed was 4.6 hours. The proportion of patients with a decline in assistance peaks for the group on treatment ≥ 6 and ≥ 9 months. The proportion of patients needing less assistance decreases steadily as patients are longer on treatment.

The higher proportion of patients on treatment ≥ 6 and ≥ 9 months is indicative of the period on treatment when patients clinically improve, adapt to treatment

and show a marked improvement in health. Interviews support this finding, as the majority of patients indicated an improvement in well being after three months of starting ART. In addition, one of medical officer's working in the PTAP programme at the PHRU noted that in her experience patients were showing clinical improvement from six months onward.

In patient interviews, the majority of the patients who required assistance due to ill health previously reported needing no assistance at all present. One patient commented, *"I used to be sick, now I am strong and do things myself. I needed help with almost every thing. Now I can do things myself".* Another patient confirmed this finding and attributed this improvement directly to treatment, *"I was sick a lot couldn't walk or sleep or cook. After ARV's its better now".* One other patient reported that when he was sick he required assistance and remarked, "*I was struggling… I could feel that there was something wrong with my body."* He states that presently, *"I actually don't ask for help because I got enough power to do whatever."*

Another patient commented, *"... in life after taking treatment you will live like any other person and you don't look like someone positive"* indicating that the improved physical appearance itself served to reduce anxiety about HIV status speculation and disclosure.

Activities requiring assistance

In phase one, cooking, cleaning, washing and dressing self and eating were activities reported by patients in which patients required the most help. One patient reported needing assistance with taking medicines; another reported needing assistance with going to the toilet, and another needed assistance with going to other places outside the house. Twelve patients reported needing assistance with laundry (washing) while one patient reported needing assistance taking care of a one-month-old baby.

Phase two interviews supported this finding as patients reported needing assistance with household chores including washing and cooking. Moreover, as one patient stated above, he needed help with *"almost everything"*.

Provision of assistance

In phase one, 'other family members' were most commonly cited as the person assisting patients with activities, followed by mothers, children and siblings. Four patients reported that partners helped with activities and two reported that friends provided assistance. One patient reported receiving help from a community volunteer. In phase two, patients cited their mothers most commonly as providing necessary assistance confirming this finding.

4.6.4.2 Episodes of Illness

The majority of patients interviewed reported that compared to before starting ART, they are experiencing less illness with most reporting no sick episodes at all. A third of the patient responses compared their well-being to those who were "*normal*" or "*healthy person*" or "*anybody else*" stating that their frequency of ill episodes was comparable to HIV negative individuals. One patient remarked, *"I am well enough now. I just get sick like anybody else"* and another remarked, *"Since I started ARV's I haven't fallen sick or been admitted at hospital"*.

4.6.4.3 Changes or Improvements on ART

In phase two interviews, patients were asked whether life has improved after starting ART, all patients responded affirmatively.

This improvement was described by the majority of the patients as an overall improvement in physical health. The majority of the patients reported that before starting ART, they were sick and two patients reported being hospitalised. Patients reported gaining weight and feeling stronger compared to previously feeling tired and weak. Some patients reported an increase in appetite and the healing of skin conditions and wounds. Patients also reported that before starting treatment, they had difficulty walking and a few more reported that they were now able to engage in household chores. This finding is consistent with clinical documentation of the benefits of ART in symptomatic HIV individuals. Evidence for the improvement in general health, weight gain

with a reduction in the frequency and severity of opportunitistic infections is clearly established (Evian 2000:80).

One patient commented, *"I was very sick, after taking ARV's I gained weight and got the power to do anything else that a healthy person can do".* Another patient remarked, *"Being on ARV's helped me a lot because before I was exposed to them I was very sick and I couldn't walk. But after taking treatment I felt very strong like anybody else".* Another patient commented, *"After I started drugs I stopped falling sick. I used to have swollen glands and used to not go to work because of weakness"*.

Only a small number of patients reported negative changes after starting ART at six and eight months. Both have documented drug toxicity, which has resulted in peripheral neuropathy.

A number of patients also reported an improvement in emotional well being after commencing ART with many remarking, *"life has changed"*. Other comments made by patients include, *"There's life after HIV/AIDS"* and *"I feel alive and always full of energy".* One patient commented, *"... I am going to live until there's a cure'.*

Another patient reports that, *"I was always crying and was worried and asking myself why me? Being sick, I was thinking I was going to die… I have two children one is 16 and the other is turning six this year… so I was thinking that I was going to lose them."* The patient explains that now, *"I feel happy … I feel alive. I am always full of energy".* She reports these improvements three months after initiation of ART. The patient reports commencing ART despite some anxiety about side effects stating that, "*people were frightening me, telling me that you have nightmares after taking them. But I told myself I wanted to try them because I didn't' want to die".* She advocates ART to other HIV positive patients explaining, "… *because they help me, if it wasn't for them I could have died. My life was not okay."* When asked what encouraged her take treatment, another patient responded, *"It's because I live better with treatment".*

When asked what caused the improvements or reported changes, most patients responded that the change was directly due to ART. Several patients attributed the improvement to ART in combination with support, adherence to treatment, good food, stopping alcohol, having a positive attitude and taking care of self. One patient reported that the *"changes were caused by acceptance of my condition".*

All patients said that they would recommend ART to other HIV positive patients needing treatment, claiming that ART was *"helpful"* and one patient added, *"A person must first be ready to take the treatment".* Patients advocate ART to others stating, *"Yes, because they* [ART] *help me, if it wasn't for them I could have died"* and "*It* [ART] *helped me a lot because now I can be proud of who I am and I can also advise other people to use the treatment and believe in them"*.

Patients were asked when they experienced these improvements in health, and majority of the responses were of three months after commencing ART. One patient reported improvement after being on treatment about one year. One patient commented, *"After two to three months after taking drugs I saw changes"*.

4.6.4.4 Conclusion

The research findings suggest that the effects of HIV at both the individual and household level are consistent with existing literature (Desmond et al, 2000; Booysen et al, 2002; Barnett & Whiteside, 2002; Bachmann & Booysen, 2003 and Naidu & Harris, 2005). Patients required assistance with basic daily activities and were assisted primarily by family members.

There is strong evidence that the quality of life improves after the commencement of ART. We can see a reversal of some of these documented effects. Fewer to no episodes of illness were reported. Patients requiring assistance at baseline reported not needing assistance and attributed this to improved health. An average of 4.6 hours a day of a caregiver's time is freed

up (mostly family members) re-directing time to other activities which increases productive capacity, making more labour available and enabling economic activity of both patient and caregiver. Time can be re-allocated toward informal unemployment or other income generating activities.

There was consensus among patients that overall improvement in health was directly due to ART with most reporting an improvement from three months after the commencement of ART. The overall perception of ART is that treatment is beneficial and patients would recommend ART to other HIV individuals. This strongly indicates that individuals are able to gain considerable benefits from ART and have the ability to resume economic activity.

5 CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This study explored the short-term socioeconomic effect of antiretroviral treatment (ART) in HIV positive patients attending the Perinatal HIV Research Unit (PHRU) Clinics in Soweto & Acornhoek, South Africa. This was primarily examined through the following two questions: what socioeconomic changes are seen on commencement of antiretroviral treatment in an eighteen-month period and how do these changes affect the ability of individuals to participate in economic activity?

This study utilised mixed methodology, combining quantitative descriptive analysis with qualitative interviews. The research was conducted in two distinct phases. Phase one entailed descriptive analysis of data on 249 patients attending the PHRU clinics in Soweto and Acornhoek enrolled in the care and treatment programmes. Changes in variables at most recent clinic visits were compared to visits prior to the commencement of ART and analysed using descriptive statistics. These variables included personal and household income, employment status, education levels, housing and assistance with daily activities. In phase two, 21 qualitative semi-structured interviews informed phase one findings by way of patient case studies. Interviews explored the changes noted by patients after the initiation of ART, the subsequent impact on their lives and the ability of patients to participate in economic activity.

5.2 Summary

This research intended to provide a descriptive overview of the socioeconomic effects on patients who had commenced antiretroviral treatment in programmes at the Perinatal HIV Research Unit and empirically concludes that despite the socioeconomic challenges in South Africa, substantial benefits are reported by patients on HIV treatment. Dominant themes uncovered in this research were of improved physical well-being and

improved quality of life. Income changes were directly attributable to changes in employment and social grants, and even though employment opportunities are not readily available in South Africa, improved health led directly to the ability of individuals to participate in economic activity. This study strongly indicates that individuals are able to gain considerable benefits from ART and are able to resume economic activity.

5.2.1 Income

The overall increase in mean personal and household income (R308 and R130 respectively) for patients who have commenced ART is suggestive of a general improvement in the ability of individuals to participate in economic activity. The notable improvement in physical health and quality of life indicate that changes in income are evident for patients on ART as early as three months. The dominant themes that emerged in patients' interviews regarding income were of employment and social grants. Income from social assistance grants was largely prevalent in the patient sample. Antiretroviral treatment enabled patients to return to both formal and informal employment and increased the capacity to actively seek employment. Empirical evidence that commencement of ART has directly (at individual level) and indirectly (at household level) led to the ability of individuals to participate in economic activity is clearly demonstrated.

5.2.2 Household Impact

Individual improvement in income and health can be directly linked to ART and therefore indirectly at the household level. However, strong evidence in favour of significant change at the household level is lacking. Changes in household size and structure, income levels and expenditure patterns as mentioned in current literature are illustrated in the research. Importantly, family members are consistently reported as providing patients with necessary support structure.

5.2.3 Change in Employment, Housing and Education

Four percent of unemployed patients reported a change in employment status after the commencement of ART. Improved well-being enabled an increase in capacity to search for employment and permitted patients to engage in informal work to generate income. Those that are unemployed are actively looking for work. Unemployment was directly related to both ill health and limited employment opportunities. The general perception is that employment opportunities are scarce and lack of experience, education and skills are barriers in securing formal employment.

For employed patients a decrease in absenteeism from work due to ill episodes and hospitalisations is noted. The illustrated benefit of ART to economic activity appears to be undermined at times by the theme of stigma and discrimination. The majority of patients believed that they could not compete equally in the employment market with those who are HIV negative.

Change in education and housing were minimal and no valuable insight was gained from patient experiences.

5.2.4 Quality of life

Nine percent of the sample required less assistance with daily activities once treatment was initiated. An average decline of 4.6 hours per day was noted implying that both patient and caregiver time was freed up. This decline peaked for patients on ART for six and nine months. Empirical evidence strongly suggests that overall improvement in health and well-being, with fewer to no episodes of illness enhanced quality of life after the commencement of ART. Patients noted an improvement in well being from three months after starting ART. Patients perceive antiretroviral treatment as beneficial and are willing to recommend it to other HIV positive individuals.

5.3 Limitations

This study investigated the research question specifically in a sample of patients in the HIV/AIDS Comprehensive Care and Support (CCS) and the PHRU Treatment Access Programmes (PTAP) at the Perinatal HIV Research Unit sites based at Chris Hani Baragwanath Hospital in Soweto, and at Tintswalo Hospital in Limpopo, South Africa. Only adult patients (16 years of age and older) were included in this research.

A small sample size of patients in both phases of the research restricts the ability to generalise the research results in other settings. The generalisation of these research findings is therefore limited to HIV positive adults with similar socio-demographic profiles residing in urban townships in South Africa.

Extraneous events were not controlled for in the design of this research. High unemployment rates, poverty and income disparity served as the socioeconomic backdrop for this research in South Africa. Other HIV infected individuals in the household of patients was not controlled for in this study. The impact at household level after the commencement of ART was investigated in brief as a significant factor affecting the overall socioeconomic impact on individuals.

The exploratory approach led to information collected in qualitative interviews that was not uniform. The broad themes probed uncovered that patient experiences differed and some preference was given to topics that concerned patients. Some patients expanded on household issues while others discussed disclosure experiences at length. Some highlighted emotional issues while others emphasised physical well-being. While the use of semi-structured interviews is useful in uncovering the ‘why’ and ‘how’ of patients circumstances it served to make comparisons between patient experiences difficult. A structured interview design with limited response category questions with a smaller number of open-ended questions would have enabled better comparison of patient experiences.

In qualitative interviews, selected patients' recall was poor at times. Patients considered the period since they had started ART as lengthy and had difficulty recalling specific information. Some contradictory information was reported which required further clarification.

In phase one, the patient data recorded at recent visits and at visits before starting ART were compared. Interim changes were consequently unidentified in the database and discovered only in qualitative interviews. Future socioeconomic data should ideally be collected and analysed at regular intervals as part of a well defined longitudinal study to prevent significant omissions.

Lastly, the length of the time on ART may not serve as a suitable predictor of socioeconomic changes and clinical criteria should serve as an alternate proxy. Individuals commence treatment at varying CD4 counts and return to physical well-being may be directly dependent on this entry point. Although ART has become more available in recent times in South Africa, many individuals have no access to testing or treatment, and this may lead to patients entering treatment programmes later than clinically appropriate. This suggests that a simplistic calculation of length of time on treatment may not always serve as an accurate indicator for when improvement in well-being is experienced.

5.4 Recommendations

HIV is a complex area of study with many facets of impact at multiple levels. Addressing treatment and its socioeconomic effect on individual well being can not be isolated from the grave reality of historically disadvantaged populations who are subject to the harsh climate of poverty and high unemployment rates in South Africa. The legacy of apartheid has led to great income disparity in South Africa and the resource constrained public health facilities necessitate that non-governmental stakeholders, private sector businesses and communities form partnerships in addressing the

comprehensive needs of individuals infected with HIV and on antiretroviral treatment.

Given the limited availability of formal employment in South Africa, and the perceived discrimination of HIV positive individuals in the workplace, it is recommended that HIV treatment clinics extend their operational hours to facilitate the collection of medication and doctor visits to hours outside of regular working hours. This further reduces the need of absenteeism from work and reduces risk of status disclosure in the workplace. It also preserves employee leave balances to be utilised for genuine vacation leave or sick leave and prevent job resignations.

Subsequent to this study, new literature (published and unpublished) on the issues discussed herein have become available and have been presented at the XVI International AIDS Conference held in Toronto, Canada. Findings from this study should be viewed in light of any new research conducted in this field.

The findings of this research strongly suggest that ART treatment is beneficial and serves to further highlight the many benefits that business alone could derive from offering ART in the workplace. The ability of individuals to continue employment, increase productivity and reduce absenteeism is evident. The possible benefit at the household level further impresses upon the potential for individual benefits of commencing ART, to cascade to a macro level.

5.5 Suggestions for Further Research

The empirical evidence presented in this study, which is widely supported by existing research on the impact of HIV/AIDS on households, necessitates that treatment and prevention efforts focus at the household level to have the greatest impact. Quantifiable studies on the socioeconomic impact of ART at both the household and individual level would be immensely beneficial in informing policy making for all stakeholders.

In addressing the socioeconomic effects of ART in HIV patients in South Africa, it is clear that addressing the benefits of ART can not be done in isolation of the bigger issues that plague this patient population, those of poverty, food security, education, skill level and most importantly unemployment. This study has grouped many different socioeconomic indicators to, broadly explore the possible future direction of research in the arena of socioeconomic impact of ART. The components investigated in this study are areas of distinct research that require in depth exploration, each indicator deserving its own comprehensive research.

Future socioeconomic research should also focus on the effect of ART beyond an eighteen-month period to better assess the long-term impact at an individual level.

The isolation of patients that no longer qualify for temporary social grants will provide valuable insight into how ART affects income. Exploring income level changes in individuals beyond the qualifying period for temporary disability grants will also provide valuable insight for policy makers and identify areas where resources and efforts should be focused. The impact on children of infected individuals requires further investigation into suitable strategies of social development beyond the provision of child grants.

Job creation for all South Africans is critical and attention to the welfare of HIV positive individuals needs attention within this context. Further research on employment for individuals on ART should also address wage scales, types of available employment, success of skills development initiatives and informal income generating activities.

5.6 Conclusion

Researchers have been plagued with concern for more than two decades about suitable ways to contain the impact of the HIV pandemic. Considerable progress has been made in global efforts to understand the virus and treat those infected with the disease. The decline in the cost of antiretroviral drugs, public treatment programmes, workplace interventions and the availability of

donor funding has improved access to treatment dramatically. The socioeconomic benefits of ART are evident and should serve to encourage stakeholders to scale up treatment efforts and embrace the goals of universal access for all HIV positive individuals. For developing nations, the provision of antiretroviral drugs and access to treatment programmes create the necessary foundation to address the bigger socioeconomic impact of the disease. However, given that numerous factors require consideration in addressing this impact, it is critical to address both HIV and its treatment efforts more comprehensively as part of the greater development agenda identified by The United Nations in its Millennium Development Goals.

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Appendix A: Data utilised from the PHRU CCS CRF

Data Source		
All pages		Study ID
Page 1		CRF version
Page 1		Visit Date
Page 1		Initials
Page 1	Question 1	Was a Consent Form Signed
Page 1	Question 2	Gender
Page 1	Question 3	Date of Birth
Page 1	Question 4	Estimated Age
Page 1	Question 5	Race
Page 1	Question 6	Town/Village
Page 1	Question 7	What is the main material that the walls of your house are built of?
Page 1	Question 8	What is the main source of drinking water?
Page 1	Question 9	Highest level of Education
Page 1	Question 10	Occupational Status
		Self Employed
		Student
		Salaried Worker
		Unemployed and able/willing to work
		Unemployed and unable/not willing to work
		Other
Page 2	Question 11	Specify your income from all non-work related sources
		None
		Old Age Pension
		Disability Grant
		Child Support Grant
		Private/Work related Pension
		Financial or non-financial gifts from household member
		Financial or non-financial gifts from non-household member
		Receiving dividends from investments
		Receiving money from business
		Other
Page 2	Question 12	How many people live in your household?
Page 2	Question 13	How many rooms are there in your house?
Page 2	Question 14	Who is the head of your household?
Page 2	Question 15	Marital status
Page 4	Question 1	Visit Date
Page 4	Question 5	Do you need help with daily activities from someone else?
	Question 5.1	If Yes - with what do you need help?
		Cooking
		Cleaning
		Washing & Dressing Self
		Eating
		Taking Medicines
		Walking around house
		Toilet
		Go to other places outside house
		Other
Page 5	Question 5.2	Who helps you with these activities?
		Mother
		Father
		Partner
		Sibling
		Child
		Other Family Member
		Friend
		Health Worker
		NGO -CBO- Church

		Community Volunteer
		Other
Page 5	Question 5.3	How many hours per day do other people help you with these activities?
Page 5	Question 6	Did any of the following change since the previous study visit?
		Education or employment
		Household head or marital status
		Housing
		Water source
Page 5	Question 9	What is your total personal monthly earnings from any source?
Page 5	Question 10	What is your household's total monthly earnings?
Page 5	Question 11	In the past week, how many times did anyone at your house miss a meal because there was no food
Page 5	Question 12	Have you disclosed your HIV status to anyone?
Page 17		Study ID
Page 17	Question 1	Is Patient on ARV Treatment at present?
Page 17	Question 2.1	HAART Start Date
Lab result	Lab result	Date
		CD4 count

Appendix B: Semi-Structured Interview Format

Patient Initials:		CCS ID (WC Number):	
DOB :		PTAP ID (PTAP Number):	
Gender:		Length of time on ART:	Months

1. Has your life improved since starting ART?
2. How?
3. *What* changes did you personally note after the commencement of ART?
4. If any, (positive or negative) *when* were these changes experienced?
5. *What* in your opinion caused these changes?
6. Would you recommend that other HIV positive individuals start treatment when needed?

The following themes were utilised to prompt participants:

- Employment
- Personal Income
- Household Income
- Household Expenditure & Levels of Savings
- Well Being – Episodes of illness
- Quality of Life – Level of assistance
- Housing
- Household make up and head
- Social Support Network – structure – new vs. old

Appendix C: Informed consent Form

STUDY NUMBER: M060433

STUDY TITLE: The Impact of ART on Individual Well-Being in Soweto, South Africa

INVESTIGATOR: Varsha Chhagan & PHRU (Dr Martinson)

INSTITUTION: Wits Business School and Perinatal HIV Research Unit

DAYTIME AND AFTER HOURS TELEPHONE (NUMBER): 083 380 0921

INTRODUCTION

Good day, my name is ……. I work at the PHRU and Wits Business School. I would like to invite you to consider participating in a research study, entitled The Impact of antiretroviral treatment on individual well being in Soweto, South Africa. Your participation is voluntary.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, and your right to withdraw from the study at any time.

If you have any questions, do not hesitate to ask me. You should not agree to take part unless you are satisfied about all the procedures involved. If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study. You will be given a copy to keep.

PURPOSE OF THE STUDY

You have been diagnosed as suffering from HIV and are on antiretroviral treatment provided by PEPFAR and previously you may have received care from Wellness. The purpose of this study is to determine the impact of antiretroviral treatment on your well being.

LENGTH OF THE STUDY AND NUMBER OF PARTICIPANTS:

The study will be performed in at the Perinatal HIV Research Clinic in Soweto and approximately 20 participants will participate in this study. The total amount of time required for your participation in this study will be a maximum of 2 hours. I will see you only once.

PROCEDURES:

If you agree to take part in this study, you will interviewed and asked questions regarding your experience on being on antiretroviral treatment. Your responses will be noted and tape- recorded. After the study is over the tapes from the interview will be destroyed.

BENEFITS & RISKS

Your participation in this study will contribute to knowledge that may help other patients that, like you, have HIV and can assist in advocating for antiretroviral treatment. There are no potential risks associated with this interview, however you may encounter some discomfort when discussing sensitive issues with regard to your HIV status and in disclosing your personal experience of being on Antiretroviral treatment. There is no benefit to you of taking part in this study.

RIGHTS AS A PARTICIPANT IN THIS STUDY

Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Your withdrawal will not affect your access to other medical care at the Perinatal HIV Research Unit.

CONFIDENTIALITY:

All information obtained during the course of this study, including hospital records, personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

The 24-hour telephone number through which you can reach me or another authorised person, is 083 380 0921. If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact the University of the Witwatersrand, Human Research Ethics Committee (HREC), which is an independent committee established to help protect the rights of research participants at (011) 717 2229.

PARTICIPANT:

Printed Name **Signature / Mark or Thumbprint**
Date and Time

I, _____ confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

I agree that the interview can be tape recorded

☐ Yes ☐ No

INVESTIGATOR:

Printed Name **Signature**
Date and Time

TRANSLATOR / OTHER PERSON EXPLAINING INFORMED CONSENT: ……**(DESIGNATION)**

Printed Name **Signature**
Date and Time

WITNESS (if applicable):

Printed Name **Signature**