

The role of HIV/AIDS disability grants in influencing people living with HIV to adhere to antiretroviral therapy with specific reference to the South African Red Cross Society in Nyanga

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Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

The first cases of HIV in South Africa were diagnosed in the early 1980s, but HIV did not become widespread in the general population until the early 1990s. Since 1994, the country has experienced an exponential rise in the number of HIV infections, AIDS diagnoses and HIV-related deaths. In 2005, an estimated 5,5 million people in South Africa were living with HIV, and an estimated 571000 new infections occurred among persons 2 years and older. In recent years HIV prevalence has stabilized as the high number of new HIV infections has been offset by a high number of HIV-related deaths. The first national estimates of HIV incidence, published early in 2008, will serve a benchmark for monitoring future trends. Social factors such as stigma, poverty, unemployment, gender inequality, migrant labour, and sexual violence are important drivers of the HIV epidemic in South Africa.

This study is a small-scale study to investigate the role of HIV disability grants in influencing people living with HIV and AIDS to adhere to antiretroviral therapy, with specific reference to the South African Red Cross Society in Nyanga. The primary objective of this study is twofold:

- (i) To determine the role of social grants in ARV adherence by people living with HIV and AIDS.
- (ii) To investigate whether people living with HIV and AIDS and using their grants are living a good healthy lifestyle

Opsomming

Die eerste gevalle van MIV/VIGS in Suid-Afrika was gediagnoseer in die vroeë 1980s, maar die virus het nie wydverspreid in die algemene populasie voorgekom nie tot die vroeë 1990s. Sedert 1994, het dié land 'n eksponensiële styging ervaar in MIV infeksies, VIGS diagnoses en MIV-verwante sterftes. In 2005, het 'n beraamde 5,5 miljoen mense in Suid-Afrika gelewe met MIV, en 'n beraamde 571 000 nuwe infeksies voorgekom tussen persone 2 jaar en ouer. In onlangse jare het MIV infeksies gestabiliseer tot die hoë aantal van nuwe MIV infeksies wat spruit uit die hoë aantal van MIV- verwante sterftes. Die eerste nasionale beraming van MIV trefwydte, gepubliseer vroeër in 2008, sal dien as 'n platform vir monitering van toekoms neigings. Sosiale faktore soos stigma, armoede, werkloosheid, geslag ongelykheid, rondtrekkend arbeid, en seksuele geweld is belangrik(e) faktore wat die MIV epidemie aanhelp in Suid-Afrika.

Hierdie studie is 'n klein-skaalse ondersoek om vas te stel hoe MIV gebreks toelae, mense se lewe beïnvloed wat MIV positief is en of dit 'n rol speel in hoe hulle hul antiretrovirale terapie (ART) volg, met spesifieke verwysing na die Suid-Afrikaner Rooi Kruis gemeenskap in Nyanga.

Die primêre doel van hierdie studie is tweevoud:

- (i) om die rol van maatskaplike toelae in ART vasklewing deur mense wat lewe met MIV en VIGS te bepaal.
- (ii) om te ondersoek of mense wat met MIV en VIGS lewe en hul toelae gebruik 'n goeie gesondheids lewenstyl handhaaf

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
DOH	Department of Health
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
PLHWA	People living with HIV/AIDS
TB	Tuberculosis
PWA	People living with AIDS
PWHIV	People with HIV
UNAIDS	United Nations Joint Program on HIV/AIDS
WHO	World Health Organization

Chapter 1: Introduction

1.1 Background font

South Africa has a well-developed system of social security and the reach of the social safety net has expanded rapidly over the past five years. Social grants are likely to play an important role in mitigating the impact of HIV/AIDS given that eligibility for these grants is driven largely by the increasing burden of chronic illness, the mounting orphan crisis and the impoverishment of households associated with the epidemic (F. Boysen, 2004).

In Sub-Saharan Africa AIDS is considered the biggest health threat of the 21st century (Kanyhama Dixon-Fyle & Claire Mulanga, 2004). AIDS is recognized as a disease, which requires more than just medical care. In the absence of a cure or vaccine, an HIV infected person is forced to contemplate death and dying. This in itself causes severe emotional distress. This distress is compounded by the fact that because AIDS is primarily sexually transmitted; it is a socially stigmatized disease, which is often wrongly associated with minority groups like homosexuals, prostitutes, drug users or black. The stigma of AIDS tends to exclude sufferers from the passion and understanding that other people with life threatening illnesses, such as cancer, benefit from. Moreover, people with HIV/AIDS have to cope with many ramifications that invariably arise from testing as HIV antibody positive.

HIV and AIDS is one of the main challenges facing South Africa today. It is estimated that of the 39, 5 million people living with HIV worldwide in 2006, more than 63% are from sub-Saharan Africa. About 5, 7 million people were estimated to be living with HIV in South Africa to date. (UNAIDS, 2008), with 18, 8% of the adult population (15-49) affected. Women in the age group of 25-29 are the worst affected with prevalence rates of up to 40%. For men the peak is reached at older ages, with an estimated 10% prevalence rate among men older than 50 years. HIV prevalence among younger women (20 years)

seems to stabilize, at about 16% for the past three years. (Department of Health, 2006 [1–2])

Fisher (1999) states that it has become generally recognized that acute and chronic medical conditions in those people living with HIV/AIDS have the potential to bring about psychological challenges; not only to patients, but also to family members, colleagues, and health workers. HIV and AIDS arguably present perhaps the most complex psychological issues of any medical condition. The overlapping of social, individual, family, financial, cultural and illness factors poses a challenge to communities and healthcare teams that strive to provide comprehensive services to the population of HIV/AIDS.

1.2 Motivation for the research

The researcher felt that there was a need to examine the role of HIV/AIDS disability grants in influencing people living with HIV in adhering to their antiretroviral treatment.

There are widespread claims that people living with HIV stop taking their antiretroviral drugs as they fear their disability grants will be stopped, while some blame the child support grant for encouraging teenage girls to become mothers.

Towards the end of 2004, the AIDS Law Project was approached by the staff of a state clinic that provides ARVs in Johannesburg. They raised the concern that the loss of disability grants might discourage people living with HIV and AIDS from starting treatment, or might provide a disincentive to adhering to their treatment regime.

The researcher strongly felt that there was a need to create a platform that will allow participants in Nyanga at the Red Cross Society Centre to express their complete thoughts and feelings on the subject of antiretroviral therapy and HIV grants. It is also

felt that better information will lead to life improvement for black women and men in the area of Nyanga.

1.3 The importance of social grants

People living with HIV and AIDS often experience multiple psychological needs and stressors. These include basic subsistence needs, as well as needs for financial assistance, psychiatric care and social support

Section 27 (1) of the South African Constitution provides that everyone has the right to access to “social security, including, if they are unable to support themselves and their dependants, appropriate social assistance. The constitution and Equality Jurisprudence indicate that the government has a positive duty to work towards substantive equality. Practically, this right has translated into the Department of Social Development providing income support to more than R50 billion people in South Africa. (Skweyiya, 2004)

If social grants are to play an important role in mitigating the socio-economic impact of the epidemic, one would expect affected households to be more dependent on income from social grants compared with the households that have not experienced morbidity or mortality. (F Booysen, 2004)

1.4 Eligibility for a disability grant

The Social Assistance Act Regulations provides the technical criteria for assessing whether a person qualifies for a disability grant or not. Section 2 (3) (1) of the 1998 Regulations sets out the criteria for a disability grant:

- The person must be 18 years or older.

- The person must have her disability confirmed by the Medical Officer or a report of an assessment panel. The report has to show whether the disability is permanent (the disability will continue for more than 12 months); or temporary (disability will continue not less than 6 months and not more than 12months).
- The degree of her/his disability must render her/him incapable of entering the labor market and she/he must not have refused employment that is within her/his capabilities.
- She/he does not without good reason refuse to undergo the necessary medical treatment.
- She/he does not already receive a social grant.

According to the AIDS Law Project when the disability grant is approved, the approval might be of a temporary or permanent status. The short-term status refers to when the condition of the beneficiary is projected to last longer than 6 months but not exceed 12 months. A letter of notification is then sent to the beneficiary of months before expiry with an advice to re-apply for appeal should the condition persists.

The long-term status means the disability will last for more than 12 months. In this case, the status of the beneficiary will be reviewed after every five years to ascertain that the beneficiary is still eligible.

Currently there is a rapid growth in the disability grant programmes, which also led to a serious backlog in terms of the review processes. The causes are that administrative and regulatory issues are part of the reason. Unfortunately this growth impacts directly on the overall national budget to the detriment of other sectors such as education and health. As a result, there is a concentrated effort on the review processes as stated in the first response. (Pooe, 2004b).

1.5 Conclusion

This chapter has indicated the importance of conducting a study of this nature especially in the Nyanga area. The importance of social grants and eligibility of disability grant was also discussed in this chapter. Ironically, in many parts of South Africa, the combination of poverty and unemployment has made HIV/AIDS one of the few remaining avenues for the short-term survival. Now, a similar perverse incentive seems to be rearing its head for many of South Africa's poor suffering from HIV/AIDS and only now receiving access to ARVs. (Simchowitz, 2002).

1.6 The objectives of the study

This study is a small-scale study to investigate the role of HIV disability grants in influencing people living with HIV and AIDS to adhere to antiretroviral therapy, with specific reference to the South African Red Cross Society in Nyanga. The primary objective of the study is twofold:

- (i) To determine the role of social grants in ARV adherence by people living with HIV and AIDS.
- (ii) To investigate whether people living with HIV and AIDS and using their grants are living a good healthy lifestyle.

Chapter 2: Research Methodology

2.1 Introduction

This chapter outlines the methodological framework used in this investigation. The first section is an overview of the interpretative; following this section is an account of the relationship between data collection and the research questions.

According to Christensen (2004) quantitative research is one that collects some type of numerical data to answer a given research question. The objective of quantitative research is to develop and employ mathematical models, theories and hypothesis pertaining to natural phenomena. The process of measurement is central to quantitative research because it provides expression of quantitative relationships. Though the research method in this study is quantitative the other part is qualitative which Christensen (2004) defines it as the interpretative, multimethod approach that investigates people in their natural environment.

2.2 Research Design

The aim of this study is to determine the role of disability grants in Antiretroviral adherence by people living with HIV and AIDS. Secondly, to investigate whether people living with HIV and AIDS using the grant are living a good healthy lifestyle.

When people who are infected with HIV/AIDS are not getting social support from their families and not even getting financial support from the government by means of disability grants it may have a negative effect on their health.

2.3 Support Group

The women and men who participated in this study were in a support group. In support groups, members provide each other with various types of non-professional, nonmaterial help for a particular shared burdensome characteristic- in this case HIV and AIDS. The help may take the form of providing information, relating personal experiences, listening to other's experiences, providing sympathetic understanding and establishing social networks. A support group also provides ancillary support such as serving as voice for public or engaging in advocacy. Support groups maintain interpersonal contact among their members in a variety of ways. Most groups have traditionally met in person sizes that allowed conversational interaction. Support groups also maintain contact through printed newsletter, telephone chains, internet forums, and mailing lists. Some support groups are exclusively online.

Members in some support groups are formally controlled, with admission requirements and membership fees. Other groups are "open" and allow anyone to drop in at the advertised meeting, for example, or to participate in an online forum.

The support group helped these women to be aware and to be more assertive about their rights. It further empowered them on how to cope with stigma and discrimination within their homes, and the challenges they face each and every day.

2.4 Sampling

The target group that was sampled for this study consisted of 20 people (18 females and 2 males) who are in receipt of social disability grant from the government, between the ages of 21 – 40, living in the district of Nyanga, Cape Town and who are on antiretroviral treatment. The participants were also receiving services from South African Red Cross Society. Random sampling was used in selecting participants from this study, which means each person in the group had an equal chance of being selected.

Table 2.1: Distribution of the ages of the respondents

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 21-25	3	15.0	15.0	15.0
26-35	11	55.0	55.0	55.0
36-40	6	30.0	30.0	30.0
Total	20	100	100	100

The participants were in a support group at the South African Red Cross Society in Nyanga and were meeting every Tuesday of each week.

More than 50% of the women that were interviewed fall into the age 26 – 35 category. Globally, 57% of all the adults infected with HIV are women between ages 15 and 24 (UNAIDS, 2004). It can be deduced from the findings of this study that women in this age group are more vulnerable to HIV infection.

One participant in the 26 – 35 age groups was diagnosed in 2005 while she was between the ages 21 – 25 years. This case supports the idea that a person may be infected with HIV well before a person becomes symptomatic and knows about the HIV status.

2.5 Data collection

Permission to conduct the study was formally approved by the Coordinator of the South African Red Cross Society. Women and men who participated in the study were also given consent letters to make sure they were willing to participate. Everything was properly explained to them before the commencement of the study.

Interviews were conducted in a spare office on the premises of the South African Red Cross in Nyanga using a semi-structured interview schedule, and participants were interviewed individually. Confidentiality was adhered to. The confidentiality procedures were explained to the participants. They were also informed that no one will access the information they have shared with the researcher. The only person who will get the results of their interviews is the thesis Supervisor and their identity would be protected since their names would not be mentioned.

2.5.1 The questionnaire consisted of four sections namely:

- i) Background and biographical information.
- ii) Perceptions of Antiretroviral (ARVs).
- iii) Attitudes of People living with HIV/AIDS and community towards HIV/AIDS.
- iv) Perceptions of HIV disability grants.

The background and biographical information contained sociode graphic characteristics including age, gender, marital status, educational level, race, employment status, number of dependants and the number of people staying in the house.

The perceptions of antiretrovirals dealt with respondents' basic knowledge of antiretrovirals such as knowing whether ARVs are curing AIDS or not. These were the closed type of questions where a respondent was required to give a response of yes or no.

The attitudes of People living with HIV/AIDS and the community toward HIV/AIDS section wanted to check how the community feels about people living with HIV and AIDS and how they feel about the pandemic.

The perceptions of social grants in people living with HIV/AIDS meant receiving disability grants is having money to buy food so that they can be able to adhere to their treatment. People living with HIV/AIDS often experience multiple psychological needs and stressors. These include basic subsistence needs, as well as needs for financial assistance, psychiatric care and social support often these psychological needs are not adequately met. Kartz et al, 2002)

2.6 The research instrument

A questionnaire was used in this study. There were mixed type of questions: open-ended and closed-ended questions.

According to Christensen (2004) an open ended question enables respondents to answer in any way they please, whereas a closed-ended question requires respondents to choose from a limited number of predetermined responses. Closed-ended questions have a finite set of answers from which the respondent chooses. The benefit of closed-ended questions is that they are easy to standardize, and data gathered from closed-ended questions lend themselves to statistical analysis.

2.7 Limitations of the study

There were a number of problems as far as fieldwork was concerned. The scheduled time for interviews took longer than anticipated. Because fieldwork was done in winter, most of the participants were not at the centre on time and others did not come at all.

The number of participants was very small so that the entire population was not represented and only two males were interviewed out of the 10 males that were supposed to be interviewed. The support group in Nyanga at the Red Cross Society had very few males who were willing to be part of the study.

Another limitation was that the study was not piloted which prevented the researcher being able to gauge what could possibly go wrong with the administration of the questionnaire.

Chapter 3: Literature Review

3.1 Introduction

People living with HIV/AIDS often experience multiple psychosocial needs and stressors. These include basic subsistence needs, as well as needs for financial assistance, psychiatric care and social support (Kartz et al., 2002) Often these psychological needs are not adequately met.

Cunningham et al., (1999) states that HIV infected individuals with unmet needs may be at risk for poorer health outcomes, as attempting to cope with these difficulties may supersede and subsequently interfere with obtaining and adhering to medical care.

The Social Assistance Act of 1992 defines a disabled person as “ any person who has attained the prescribed age and is, owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession by means needed to enable him or her to provide for his or her maintenance.”

A number of people living with HIV and AIDS (PWAs), but by no means all who need it, have been able to access social assistance in the form of a monthly disability grant. With the announcement of a public sector antiretroviral (ARV) roll out plan (Department of Health, 2003), substantially more PWAs who rely on the public health sector have access to life saving medicines than in the past. This has given rise to a situation where PWAs who take ARVs and become well are in danger of losing a disability grant that in many cases provides access to basic (life-saving) services and food, not only for themselves, but for the extended families.

Recently, the national Department of Social Development has begun tightening restrictions on disability grants throughout the provinces, claiming that too many people are using grants as a form of poverty alleviation.

HIV and AIDS is one of the main challenges in South Africa today. It is estimated that of the 39.5 million people living with HIV worldwide in 2006, more than 63% are from Sub-Saharan Africa. About 5.7 million people were estimated to be living with HIV in South Africa to date (UNAIDS, 2008), with 18,1% of the adult population (15 – 49) infected. Women are disproportionately affected; accounting for 56% (3.2 million) of HIV people. Women in the age group 25 – 29 are the worst affected with prevalence rates of up to 40%. For men the peak is reached at older ages, with an estimated 10% prevalence among men older than 50 years. HIV prevalence among younger women (<20 years) seems to be stabilizing at about 16 % for the past three years. (Department of Health, 2006 [1 – 2])

This chapter informs the reader on research done on the subject of Antiretroviral HIV grants and adherence in the surrounding areas and Southern Africa.

3.2 Grants and ARVs

Hardy and Ritcher (2005) state that most people do not understand that if they start ARV treatment and get better, they will lose their disability grant. Natrass (2006) proposes that government should continue providing the disability grant to PWAs even after they become healthy on ARVs.

However, social security may be inappropriate in a society with widespread poverty and unemployment. Most grant recipients use their grants to support their immediate and sometimes extended families, and the grant is often the family's only source of income. However, it is difficult to see how these alternative social assistance programmes will adequately meet the needs of people living with HIV who have no immediate prospect of employment, and who have lost disability grants because their health improved due to ARV treatment. (Hardy, 2004 October – January 2005).

3.3 Unemployment and disability grants

In the context of high unemployment and the general confusion and ambiguity surrounding HIV/AIDS and disability grants, many poor South Africans, both HIV positive and negative, have tried to use the disability grant as a source of income. Many with HIV have gone to primary health clinics hoping for a disability grant recommendation from their doctor, only to be turned away. (Simchowitz, 2004).

These are widespread claims that people with HIV stop taking antiretroviral drugs as they fear losing their disability grants, while some blame the child support grant for encouraging teenage girls to become mothers. However, preliminary research by the Department of Social Development into these claims has found no evidence to support the claims.

In November 2003, the South African government announced its intentions of rolling-out a public sector antiretroviral (ARV) plan. Some progress has been made in a number of provinces, with substantially more PWAs dependent on the public sector health system being able to access ARVs than in the past. This has given rise to a situation where PWAs who are disability grant recipients and have become better on the ARVs, are no longer eligible for the disability grant.

3.4 Adherence

As there is at present no cure available for patients with HIV and AIDS, they usually need a lifetime of treatment. This means that adherence is vital: Adherence means taking your medications correctly. If one is not taking treatment correctly HIV might multiply out of control. Adherence medication must be taken according to the instructions – the recommended dose, at the recommended time, and in the recommended way.

Suboptimal adherence may result in reduced treatment response. Incomplete adherence can result from complex medication regimens; patient factors such as active substance abuse and depression; and health system issues, including interruptions in medication access and inadequate treatment education and support. Conditions that promote adherence should be maximized prior to initiating antiretroviral therapy.

The advent of highly active antiretroviral therapies (HAART) in 1995/996 ushered in a new era in the management of HIV pandemic, with new drugs, new strategies, new vigor from treating clinicians, and enthusiasm on the part of their patients. Mortality and morbidity figures dropped radically, with associated gains in cost benefits with regard to macro- and microeconomics costs. What soon became evident, however, was the vital importance of patient adherence with prescribed medication in order to garner the benefits that were so rapidly becoming available. As a result, much attention has recently been paid to this aspect of management (Andrews, 2002).

A study conducted by the University of Pretoria (2005) on the ARV roll-out states that the success of the ARV programme will depend on a number of factors, including the readiness of the individual to embark on treatment, adjustment to being on treatment, an ability to adhere to medications on the capacity to deal with treatment change or failure. All of these stages require emotional support of family and friends. This is complicated by the challenges of disclosure – ideally someone on treatment should have disclosed to a person who can support their adherence to treatment; someone in the household.

Sidat et al., (2007) points out strict adherence to antiretroviral treatment regimes is critical to effective management of HIV disease, because of the rapid rates of HIV replication and mutation. Consequently, failure to follow the dosing instructions of prescribed regimens can lead to selection of resistant quasispecies and incomplete viral suppression.

Lack of disclosure, food insecurity, meal restrictions, side effects, toxicity and a poor psychological environment are the main barriers to adherence.

3.5 Patient preparedness

Andrews (2002) highlights the fact that patient preparedness is the most important factor in beginning therapy, and is vital to ongoing adherence to antiretroviral agents. Education regarding the illness itself, the benefits and drawbacks of antiretroviral and other therapies, and the longstanding nature of such therapy, needs to be exhaustive and ongoing. Patients should be given sufficient time to consider the personal ramifications of taking medication lifelong, as well as the associated issues of confidentiality, disclosure and social stigma that may impact on their decision.

Follow up consultations, with family and caregivers if possible, can assist in this process. This is generally true in all settings, but particularly if medication is commenced in the presence of index patient dementia or other illness, for example TB or meningitis that may impair memory and mentation. Carers may assist with medication administration until such time that the patient is able to take it independently, in addition to providing ongoing practical and emotional support.

It is important to recognize that some degree of nonadherence is common and should be expected in all patients who are receiving therapy. Strict adherence to antiretroviral treatment is critical to the effective management of the disease. Patients who incompletely adhere to antiretroviral therapies can be expected to experience higher rates of disease progression in comparison to patients who take antiretrovirals as prescribed.

3.6 Conclusion

In conclusion, the literature suggests that HIV patients' readiness for successfully starting HAART can be enhanced by providing patients with a psycho-educational readiness adherence intervention to initiate HAART. People living with HIV/AIDS should be given the opportunity to be involved in choosing, starting, and maintaining control of the HIV/AIDS virus. The medication should however be seen as a form of benefit.

Individuals need to justify their behavior. The Patient's belief should be examined and corrected if necessary. Patients who feel better informed and more actively involved in making treatment decisions adhere better to that treatment

Chapter 4: Presentation of Results

4.1 Introduction

HIV/AIDS is one of the most devastating diseases to have emerged in recent history. Although worldwide there are no great disparities in HIV prevalence between women and men, gender inequalities and biological factors make women more vulnerable to HIV/AIDS compared to men (WHO, 2007).

In South Africa, HIV/AIDS has proven to be a great threat to the state of health of its people. According to the Burden of Disease study (MRC, 2005) South Africa is plagued with a quadruple burden of disease due to HIV. OF this burden, HIV is the leading cause of mortality in the country. Other studies (Shisana et al., 2005) also indicate that women are more affected than men. These types of findings make it crucial to study and understand this pandemic.

When looking at the gender inequalities related to women and HIV, socio-economic factors become an important factor on one hand. On another hand, socio-economic factors, through intrinsic, interpersonal and environmental factors, influence health behaviors (Liang et al., 1999). It is within this premise that we studied the relationship between HIV/AIDS and social grants, which are the Government's way of assisting/supplementing poor households with income.

This chapter provides an overview of the study participants' biographical data, their knowledge, attitudes and perceptions as HIV-positive people, on their experiences and understanding of Government's interventions to assist people infected with HIV/AIDS. In terms of Government's intervention, focus is placed on antiretroviral treatment and social grants.

4.2. Findings

This section presents the findings of the study under various sub-headings following the logic of the questionnaire. It substantiates the findings with literature.

4.2.1 Biographical Information

- **Age**

The age group between 26 and 35 years form the largest component of the participants in this study (See table 4.1). This group is followed by participants in the age group 36 to 40 years, and thereafter 21 to 25 years.

Table 4.1: Age

		Frequency	Percent
Valid	21 – 25	3	15.0
	26 – 35	11	55.0
	36 – 40	6	30.0
	Total	20	100.0

One participant in the 26-35 age groups was diagnosed in 2005 while she was between the ages 21 & 25 years. This case supports the idea that a person may be infected with HIV well before a person becomes symptomatic and know about the HIV status.

More than 50% of women participants fall between the ages 26-35 year category. The findings therefore suggest that more women in this age group are infected with HIV in this study. Globally, 57% of all the adults infected with HIV are women between 15 and 24. (UNAIDS, 2004), which means that women in this study were infected earlier. It can also be deduced from the findings of this study that women in this age group are more vulnerable to HIV infection in their early years.

- **Gender Distribution**

The next table reflects the gender distribution of participants in the study. The results indicate that 90% of the study participants are females. The results of the study seem to confirm the assertions and findings of other studies that more women are infected by HIV in comparison to men. It also reflects that women are more open about their HIV status and receptive to assistance than men. The support groups are open to all persons living with HIV but women are the ones who dominate these groups. This is a phenomenon that is experienced in other studies as well. On the contrary, men tend to be secretive about their HIV status which in turn determines the help seeking behavior and the ability to disclose their HIV status to others.

Table 4.2: Gender Distribution

	Frequency	Percent
Male	2	10.0
Female	18	90.0
Total	20	100.0

According to UNAIDS, 2004 young women are 1.6 times likely to be infected than men and 2.5 more times in Africa. It also suggests that women are more open about their HIV status than men, and making them more likely to reach out for help and support from social systems and networks at their disposal.

Although worldwide approximately as many women as men are living with HIV, gender inequalities as well as biological factors make women more vulnerable to HIV and to the impact of AIDS than men (WHO, 2007). The South Africa national household survey found that 33% of young women were afraid of saying no to sex to their partners. Various factors have been attributed to greater vulnerability of women to HIV infection than men. These include women's biological make up that exposes them to greater infection during intercourse; social norms that emphasize female chastity and condone male promiscuity; cultural factors that may favour early pregnancy and discourage

condom use or facilitate intercourse with older men who are likely to be infected; unequal partnerships that accept female subservience and male dominance; violence against women as well as the economic dependency of many women on men for their survival and the greater recourse to prostitution by women seeking economic survival (Bagnol & Chamo, 2004)

Ghosh & Kalipeni (2005), who support some of the findings of the household survey, suggest that gender inequalities play a crucial role in the spread of HIV, as women are both physiological and socially more vulnerable to infection than men. Women are bound by culture not to leave or divorce their husbands even when the husband does not provide economic support, is unfaithful, and has AIDS.

- **Marital Status**

The relationship between marital status and HIV infection is complex. It is largely dependent on various demographic factors, and sex behaviour practices adopted by a person (Shisana et al, 2004). Thus prevention strategies need to be focused on these identified sex behaviour practices; take into cognisance the socially constructed and accepted socio-cultural practices.

Table 4.3: Marital Status

		Frequency	Percent
Valid	Married	3	15.0
	Single	14	70.0
	Divorced	3	15.0
	Total	20	100.0

This study reveals that more single persons (70%) were the most dominant participants, also reflecting on their vulnerability to HIV infection than married and/or divorced persons. This finding supports the finding by Shisana et al (2004). The risk of HIV

infection and marital status are closely linked. Shisana (2004) found that the risk of HIV infection was higher among unmarried than married persons. The authors also found that married men were at higher risk of HIV infection than married women, suggesting that married men also engage in extra-marital sexual relationships.

- **Employment**

Lack of employment is identified as one of the drivers of HIV infection especially in people of working age. A study conducted in London in 2008 revealed that many people living with HIV in London are unemployed and live in poverty.

Table 4.4: Employment

		Frequency	Percent
Valid	Yes	6	30.0
	No	14	70.0
	Total	20	100.0

Seventy percent (70%) of the participants are unemployed, with only 30% reporting to be employed. Literature suggests that people living with HIV always are concerned about unemployment. Lack of employment aggravates socio-economic status and needs of people living with HIV/AIDS.

- **Number of Dependants**

A question on the number of dependants have provides information on the responsibilities that the participants have. Also, the number of dependants could point out to the levels of difficulties that the participants experience which is also an important indicator of poverty.

Table 4.5: Number of Dependants

		Frequency	Percent
Valid	Yes	16	80.0
	No	4	20.0
	Total	20	100.0

Eighty percent (80%) of the participants have dependants that they have to provide for even in the presence of the illness and associated difficulties. Twenty percent (20%) do not have dependants to take care of. A UNICEF study done in India found that children’s wellbeing is affected and/or experience certain barriers when parents are living with HIV or died of AIDS related diseases. The barriers include receiving advice and emotional support; influencing decisions that affect their lives; how they are raised; and other essential services like education and medical care (UNICEF, 2007).

- **Educational Achievement**

In 2007, in a study conducted in Lesotho by the World Bank found education has a protective factor; is negatively associated with HIV infection; and strongly predicts preventive behaviours.

Table 4.6: Type of Education

		Frequency	Percent	Cumulative Percent
Valid	Some Primary	3	15.0	15.0
	Some Secondary	10	50.0	65.0
	Grade 12	6	30.0	95.0
	Tertiary	1	5.0	100.0
	Total	20	100	100.0

The findings show that 50% of the participants have some secondary school educations, 30% has grade 12, and 5% has tertiary education. In the South African schooling system, grade 12 is a requisite for entering tertiary institutions like the university/college. It is therefore concerning that people (30% in this study) who are eligible for tertiary education find themselves infected with HIV. Infection with HIV is often associated with loss of opportunities for better education and development, which are supported by the findings of this study.

A cumulative percentage of participants (65%) have either primary or secondary education, which make their chances of improving their lives much less. Among this group of participants, receiving a social grant could be seen as one way of providing social security and relieving poverty. Social grants are therefore a form of financial support and safety net. The results also confirm the World Bank findings that negatively link education to HIV infection.

- **Year of HIV diagnosis**

This section focuses on the year in which the participants were diagnosed with HIV. The question helps in understanding and knowing the number of years in which the person has been living with HIV. It also demonstrates the experience of HIV, and possibly giving some rich information on the needs of people living with HIV/AIDS and the need for social assistance in particular.

Table 4.7: Year of first diagnosis

		Frequency	Percent	Cumulative Percent
Valid	1998	1	5.0	5.0
	2000	3	15.0	20.0
	2001	3	15.0	35.0
	2003	5	25.0	60.0
	2004	4	20.0	80.0
	2005	3	15.0	95.0
	2006	1	5.0	100.0
	Total	20	100.0	

The majority of participants (45% combined) were diagnosed with HIV in 2003 and 2004, making them living with the disease for 3 to 4 years now. Only one participant is living with HIV the longest (9years) having been diagnosed with HIV in 1998. By implication, the participants have wealth of information on the experience of HIV which has led to many of them applying for the social grants to assist them in coping with the disease.

4.2.2 Attitudes of People Living with HIV/AIDS (PLHWA) and the community towards HIV/AIDS

Stigma and discrimination play a significant role in development and maintenance of HIV/AIDS epidemic. It is well documented that people living with HIV and AIDS experience stigma and discrimination on an ongoing basis. (Skinner and Mfecane, 2004) This impact goes beyond individuals infected with HIV and AIDS to reach broadly into the society.

According to Kekana stigma delays the engagement of people with HIV/AIDS testing and access to prevention and treatment facilities for HIV/AIDS. Stigma drives HIV/AIDS out of the public sight. That, however, reduces the pressure for the community

and their own homes; they are frequently blamed for infections and are at risk of violence.

One of the participants during the interview highlighted the fact that the community should be properly educated about HIV/AIDS because the participant felt that there was still a lot of discrimination from the community.

Additionally, the stigmatized often blame themselves. A recent USAID paper stated that “the stigmatized often accept the norms and values that label them as having negative differences. As a result, stigmatized individuals or groups may accept that they “deserve or ought” to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult.

4.2.3 Perceptions about Antiretroviral Treatment

Table 4.8 Do you think ARVs can cure the disease?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	1	5.0	5.0	5.0
No	19	95.0	95.0	95.0
Total	20	100.0	100.0	100.0

About 95% of the participants felt that antiretrovirals cannot cure the disease, but do prolong a person’s life. However, one participant believes that antiretroviral actually provided a cure for the illness. This has implications for the education of people about HIV and treatment as they might live with false assumptions about the cure for the illness. On the other hand, the educational programmes aimed at people living with HIV seem to be working, with the majority of the participants’ knowledge that the ARVs provide no cure for the illness.

Given the fact that HIV/AIDS in South Africa is such a debilitating problem, South African social assistance legislation makes no mention of it, even in the context of

disability grants (Simchowitz, 2004). As a result abounds as to when an HIV or AIDS diagnosis qualifies a poor South African for social assistance. Those suffering from an advanced stage of the disease (stage 4 as defined by the World Health Organization’s guidelines) are symptomatic with serious opportunistic infections and are often bed-ridden for the most of the day. These people are unable to work by any definitions, and the Western Cape Department of Social Services has historically provided them with disability grants.

Clinical stages 1, 2 and 3, however, are more ambiguous and may or may not be marked by symptoms and weight loss. In addition, people living with HIV and AIDS may have abnormally low CD4 counts without exhibiting symptoms. The Centre for Disease Control and Prevention (CDC) consider an HIV infected person with a CD4 count of less than 200 cells per cubic millimetre of blood to have AIDS, regardless of whether they feel sick or healthy. It is possible, then, that someone in stage 1 or 2 according to clinical WHO guidelines could have a dangerous low CD4 count.

4.2.4 Perceptions about HIV grants

Section 27 of the South African Constitution guarantees everyone the right to have access to health care services, sufficient food and water as well as social security.¹ Equality and dignity are both substantive rights and the fundamental values that underlie the constitution.

Table 4.9 Social grants as a motivator for taking antiretrovirals

	Frequency	Percent
Yes	18	90.0
No	1	5.0
Not stated	1	5.0
Total	20	100.0

Study participants were asked whether they thought a social grant helped them with taking their antiretrovirals (ARVs). Table 4.3 shows that from all the study participants,

¹ Constitution of the Republic of South Africa. Act No. 106 of 1996.

90% of them believe that having a social grant is a motivating factor for taking treatment though 5% of the participants believe that there is no link between taking ARVs and receiving a social grant. According to Booysen (2004) if social grants are to play an important role in mitigating the socio-economic impact of the epidemic, one would expect affected households to be more depended on income from social grants compared to households that have not experienced morbidity or mortality.

People should be properly educated more about social grants so that they can understand what it means to get social support. When study participants were asked about their understanding of social grants, this became evident. The following extract was taken from one of study participants:

Having the grant is financial support from the government and it helps me buy food so that I can take treatment with food not in an empty stomach. (Participant 12)

Some of the participants are aware that when one becomes better and the CD4 count goes up that the grant will be taken away from them hence others do not adhere to treatment. This indicates that there is need to have support interventions for people living with HIV, so that they do not compromise on their health and well-being for the sake of receiving social grants.

4.2.5 Poverty and HIV/AIDS

Further look at the results of this study, one can deduce poverty experienced by the group of HIV positive persons who participated in the study. As much as 70% of the participants are not employed, 80% have dependants, and a cumulative 95% of the participants have primary and secondary education. Out of this 95%, 30% have managed to achieve grade 12 which is a prerequisite for entering tertiary education. It also means that these people are trapped into poverty, and without assistance they are likely to sink deeper into poverty.

Poverty and HIV and AIDS are interrelated. Poverty is a key factor leading to behaviors that expose people to the risk of HIV infection, and poverty exacerbates the impact of HIV/AIDS (Cohen, 2000). The experience of HIV and AIDS can readily lead to an intensification of poverty and can push people further into poverty. Poverty, according to World Bank (2003), is rooted in various dimensions which include low income, lack of education, environmental degradation and gender equality. Thus, people who earn a low income, are uneducated, live in dire physical/social conditions and are females, are more affected.

Poverty deprives individuals of the means to cope with HIV and AIDS. The poor lack the knowledge and awareness that would enable them to protect themselves from the virus, and, once infected, they are less able to gain access to care and life-prolonging treatment (Tladi, 2006).

The socio-economic impact of HIV and AIDS serves to create a vicious circle of poverty and disease. If the household breadwinner becomes ill and is forced to give up his/her job, the household income will fall. To cope with the change in income and the need to spend more on health care, children are often taken from school to assist in caring for the sick or to work so as to contribute to household income. Because expenditure on food comes under pressure, malnutrition often ensues, while access of other basic needs such as health care, housing and sanitation may also come under threat. Therefore HIV and AIDS and the associated burden of morbidity and mortality expose already vulnerable households to further shocks. (Cohen, 1998).

4.3 Summary of findings

It is important to recognize that some degree of non-adherence is common and should be expected in all patients who are receiving antiretroviral therapy. Adherence to treatment is crucial for long-term management of the disease and should be encouraged. Starace et al (2000) found that HIV positive patients showed higher levels of depressive symptoms than adherent subjects; and is associated with lower family and community support.

The main finding in this study is that 95% of the participants understood that antiretroviral does not cure the illness but rather prolongs a person's life. The participants also learned that if they adhere to the treatment they will live a normal, healthy life like any other person. However, it was also found that there are people who believe that ARVs are a cure for HIV. This has implications, in that it highlights the need to educate people about HIV and treatment. By doing so, we would be avoiding a situation whereby people live with false assumptions about HIV/AIDS.

It is important to note however, that there are educational programmes which are aimed at people living with HIV. Such programmes include, Soul City, Khomanani, TshaTsha and loveLife. These programmes are targeted at various age groups and focus on various aspects of HIV awareness. These programmes are generally well-received and meeting their goal of raising awareness among South Africans about HIV/AIDS, as more-and-more people are becoming aware that ARVs are not a cure for HIV.

From this study, 90% of the participants were females. This finding seems to confirm the assertions and findings of other studies that more women are infected by HIV compared to men (UNAIDS, 2007 & HSRC, 2005). It also reflects that women are more open about their HIV status and receptive to assistance than men. This study confirmed that although support groups are open to all persons living with HIV, women are the ones who dominate these groups.

In this study, more single persons (70%) participated compared to married (15%) and divorced (15%) couples. The age group of 26 – 35 years forms the largest component of the participants in this study. This group is followed by participants in the age 36 – 40 years of age category and thereafter 21 – 25 years of age category. All the participants were Africans as this study was conducted in Nyanga, a black township in Cape Town.

Most of the study participants in this study were unemployed (70% versus only 30%). From this group, 80% reported that they had dependants, which means that irrespective

of their employment status they had to provide for others. In this case, it was reported that study participants had 4 or more persons staying with them. This was the fact even for those who experienced difficulties with their illness. This then means that the grant is being used to support their families and sometimes their extended families, and the grant is often the family's only source of income.

This study's biographical data shows that 50% of the participants had some secondary education, 30% had grade 12 and 5% had tertiary education.

Of all the study participants 90% (n=19) of them reported that they believe that having a social grant is a motivating factor for taking antiretroviral therapy; and 5% (n=1) reported that they believed that taking ARVs is not motivated by receipt of a social grant.

The majority of study participants (75%) believe that the social grant amount provided by Government is not enough. Only 25% of the study participants reported that they believe that Government provides sufficient social grant amount. However, it is interesting to note that those who reported that Government provides a sufficient social grant were employed participants. Thus, the social grant for the employed study participants is an additional (or extra) income. This is the group that also reported that they felt that the grant serves as motivation for them to adhere to their HIV treatment, as it allows them to be able to buy food. Also this makes it easier for them to take their treatment regularly.

Chapter 5: Conclusion and Recommendations

5.1. Conclusion

From the narrow point of view, PLWHAs who are disability grant recipients, but who become well, are capable of working. Under South African legislation and policy, therefore, they are not entitled to retain their disability grant.

The lack of support for the poor in South Africa has led working age adults to look to the disability grant as their only potential source of income. The government's financial assistance by means of grants to people who are HIV motivates them to adhere to their treatment.

Ironically, in many parts of South Africa, the combination of poverty and unemployment has made HIV/AIDS one of the few remaining avenues for short-term survival. Now, a similar perverse incentive seems to be rearing its head for many of South Africa's poor suffering from HIV/ AIDS and only now receiving access to ARVs (Simchowitz, 2004).

This study has limitations which include the sample size, location of the study, and lack of incentives. The study has a sample size of 20 participants. Although it was difficult for the student to reach and recruit HIV positive persons for various reasons, the sample size can be increased to reach out to as many participants as possible. However, sufficient time is required to reach this target group as it proved difficult for the student to access HIV positive persons through support groups.

The location of the study is another limitation of the study. This was largely due to insufficient funds to expand to other locations around Cape Town. Therefore, a study of this nature would require more funding to overcome the difficulties that the student faced in the conduct of this study.

Also, it proved that the lack of incentives for the participants weighed heavily on the number of participants that could be reached. This is attributed to the fact that Nyanga is

an area that many research studies are conducted and incentives given to those who participate in them. It means that potential participants are used to incentives and studies that do not give incentives are jeopardized by this fact. Again funding is required to make provision for these incentives.

5.2 Recommendations

Recommendations are divided into two sections focusing on 1) policy and programmatic interventions; 2) and future research. The following section thus sets out the recommendations.

5.2.1 Policy and Programmes

- Ongoing training on treatment adherence should be encouraged. In other words patients should be taught how important taking their treatment is.
- Strategies for intervention are likely to be based on tailoring the drug regimen to the lifestyle of the patient and assessing adherence as part of a follow up program.
- The department of health and the department of social development should work together more closely to ensure that every PWA who takes treatment is able to access appropriate, healthy and adequate food, as well as water.
- Ongoing monitoring is needed to evaluate the impact of rolling-out the National ART plan, to assess the optimal time to start treatment, to evaluate new treatments, and to minimize the incidence of side effects and drug-resistant infections.

5.2.2 Future Research

- A qualitative study is required to further understand the needs of people living with HIV/AIDS to help devise interventions that speak to their qualitative needs.
- Encourage population based studies done in all provinces.

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Appendix

Appendix A: Consent Form

Hello, I am Ncane Ndlumbini I am from the University of Stellenbosch. Our university is asking people from your organization to answer a few questions, which we hope will benefit your community and possibly other communities in the future.

The university is a national research organization, and we are conducting research regarding the role of HIV/AIDS disability grant in influencing people living with HIV to adhere to ARV with specific reference to South African Red Society.

Please understand that your participation is voluntary and you are not being forced to take part in this study. The choice is whether to participate or not, is yours alone. However, we would really appreciate it if you do share your thoughts with us. If you choose not to take part in answering these questions, you will not be affected in any way whatsoever. If you agree to participate, you may stop me at any time and tell me that you do not want to go on with the interview. If you do this there will also be no penalties and will NOT be prejudiced in ANY way.

I will not be recording your name anywhere on the questionnaire and no one will be able to link you to the answers you give. Only researcher will have access to the unlinked information. The information will remain confidential and there will also be no “come-backs” from the answers you give.

The interview will last around 20 minutes. I will be asking you a few questions and request that you are as open and honest as possible in answering these questions. Some questions may be of a personal and/or sensitive nature. You may choose not to answer these questions. I will also be asking some questions that you may not have thought about before, and which also involves thinking about the past or future. We know that you cannot be absolutely certain about the answers to these questions but we ask that you

try to think about them. When it comes to answering these questions, there are right and wrong answers. When we ask question about the future we NOT interested in what you think the best thing would be to do, but what you think would actually happen.

If possible, our university would like to come back to this area once we have completed our study to inform you and your organization of what results are and discuss our findings and proposals around the research and what this means for people in this area.

Consent Form

I hereby agree to participate in research regarding the role of HIV/AIDS disability grants in influencing people living with HIV to adhere to ARV with specific reference to South African Red Cross Society in Nyanga. I understand that I am participating freely and without being forced in any way to do so. I understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this research project whose purpose is not necessarily to benefit me personally.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

I understand that if at all possible, feedback will be given to my organization on the results of the completed research.

.....

Signature

.....

Date

Appendix B: Interview Schedule

Study on the role of HIV/AIDS Disability grants in influencing people living with HIV to adhere to Antiretroviral with Specific reference to South African Red Cross Society in Nyanga.

This survey is completely anonymous. Please do not put your name anywhere on it.						
Ms N. Ndlumbini of Stellenbosch University is conducting this survey.						
The information in this survey will not be given to anyone in your community.						
Please circle your answer to each question below:						
Biographical information						
1. What is your age:	21-25	26 - 35	36 - 40			
2. What is your gender?	Male	Female				

3. What is your Status?	Married	Single	Divorced		
4. Which best describes you?	African	White	Coloured		
5. Are you employed?	Yes	No			
6. Do you have dependants?	Yes	No			
7. How many people are staying in your house?	1 2	3 4	5 6 or more		
8. Do you have any children?	Yes	No			
9. What is the highest level of education that you have completed?	No schooling	Some primary	Some secondary	Grade 12/ Std 10	
10. When did you first test HIV/AIDS?	Month	Year			

11. What is your attitude towards HIV/AIDS? _____						
12. What is your community's attitude towards living with HIV/AIDS? _____						
13. What is the community's attitude towards people living with HIV/AIDS _____						
Perceptions of ARVs?						
14. Are you currently taking antiretroviral (ARVs) medication? _____						
15. Do you think ARVs can cure the disease _____						
16. Which best describes your current health? _____						
17. Have you ever attended a support group? _____						
Perceptions of Social Grants?						
18. Do you understand the meaning of HIV grants? _____						
19. Do you think having a grant is helping you in taking your antiretroviral?						

20. Do you think government is giving enough money?						

21. Does the grant motivate you in adhering to the treatment?						
