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**The Role and Function of a Disability Grant and perceived benefit for persons on HAART in Masiphumelele Community**

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## **Declaration**

I, Helen Louise Woolgar, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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## **Abbreviations and definition of terms**

AIDS:	Acquired immune deficiency syndrome
ART:	Antiretroviral therapy
ARVs:	Antiretroviral medications
BIG:	Basic Income Grant, a proposed monthly grant that would be paid by the State to everyone legally resident in South Africa, regardless of age, income, family status, or other factors. To date this has not been implemented.
CNP:	Clinical nurse practitioner, a nurse trained (postgraduate qualification) in diagnosis and treatment prescription in the South African setting, as described in the Nursing Act, 2005, section 31 (1). Regulation 1379 pertains to the training of clinical nurse practitioners.
DTHF:	Desmond Tutu HIV Foundation, a registered non-profit organisation focused on the pursuit of excellence in research, treatment, training and prevention of HIV and related infections in Southern Africa. DTHF is based in Cape Town and is run in association with the Desmond Tutu HIV Centre and University of Cape Town's Institute of Infectious Disease and Molecular Medicine. The Foundation operates community sites in greater Cape Town's Nyanga and Masiphumelele clinics. URL: <a href="http://www.desmondtutuhivcentre.org.za">www.desmondtutuhivcentre.org.za</a>
FGDs:	Focus group discussions
HAART:	Highly active antiretroviral therapy
HIV:	Human immune-deficiency virus
PLWHA:	People living with HIV/AIDS
PMTCT:	Prevention of Mother-to-Child Transmission (of HIV)
TB:	Tuberculosis
WHO:	World Health Organization

## **Abstract**

In the context of the HIV/AIDS pandemic in South Africa Disability Grants are playing a major role in alleviating poverty. In HIV-affected households in the community of Masiphumelele in Cape Town they are most often the only source of income. The high unemployment rate in South Africa together with limited welfare provision may result in HIV-infected persons having to face the dilemma of losing a grant or continuing to adhere to highly active antiretroviral therapy (HAART) once clinically stable with an undetectable viral load. Non-adherence could lead to drug resistance and would thus be detrimental to health, with increased risk of infection and a higher burden of care. Persons who adhere to the antiretroviral (ARV) regime are more likely to have a reduced viral load and an increase in CD4 count, which results in the loss of the Disability Grant since they are then classified as able to work.

## **Aim of the study**

The aim of this study is to explore HIV positive persons' perceptions of the usefulness of Disability Grants and their contribution to health and well-being while on HAART.

## **Objectives of the study**

- To determine perceptions of the purpose and function of Disability Grants among persons who are HIV positive in the Masiphumelele community.
- To explore with participants whether their perception of Disability Grants may affect decision-making with respect to adherence to ARV therapy

## **Research design**

This qualitative research design explored HIV-positive persons' perceptions and understandings of Disability Grants. Three focus group discussions (FGDs) were conducted with 15 purposively selected participants from among patients who attended the Masiphumelele Clinic. FGD one comprised adults on HAART for more than 6 months who were receiving Disability Grants; FGD two comprised adults on HAART for more than 6 months whose grants had been terminated because their CD4 counts were  $>200$  cells/mm<sup>3</sup>; and FGD three comprised adults on HAART for more than 6 months who had never received a Disability Grant because their CD4 counts were  $>200$  cells/mm<sup>3</sup>.

Five general questions and four to six specific questions were asked of each focus group. All ethical considerations were adhered to, in particular that of confidentiality. The FGDs were recorded and transcribed. A thematic data analysis approach was used.

### **Findings and recommendations**

Two major themes emerged: Disability Grants as a means of survival, and Disability Grants and their role in HAART. The Disability Grant is considered an essential source of income, and for some is the sole means of survival. The participants in this study felt that the awarding of social assistance should go beyond the Disability Grant and be extended to those who are unemployed as well as those living in poverty. Four of the 15 participants had become non-adherent to HAART in order to access a Disability Grant. This non-adherence to HAART was used as a means of survival. Overall findings indicate that HIV-positive persons in Masiphumelele value their health and that of their children more than becoming non-adherent to HAART in order to access a Disability Grant.

The perception of the value of the Disability Grant – as not only being for those who qualify through eligibility of illness/disability criteria, but a regular income support – needs to be considered by the relevant governmental structures. The need for appropriate skills development is evident: for young people in particular, suitable training for employment in the labour force is an urgent need. Although this is a recognised need for all unemployed, it is particularly important for persons with a chronic illness such as HIV to reduce their feeling of dependency and allow them to provide for support themselves and their families.

Innovative strategies involving all relevant stakeholders are required to support people living with HIV/AIDS and ensure that they are able to support themselves for as long as possible, and that there is an appropriate support structure for the periods when they need social assistance.

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# Chapter 1

## Introduction

### 1.1 Introduction and background to the study

In South Africa social grants, of which the Disability Grant is one, are an important source of income for households with very limited means. South Africa has one of the highest HIV rates in the world, with around 5.7 million people estimated to be living with the virus. This figure represents about 12% of the South African population (Health Systems Trust 2010). The socio-economic impact of HIV/AIDS exacerbates a cycle of poverty and disease. Adults who become infected will become ill, which can result in loss of employment due to incapacity. Natrass (2004) reported an alarming increase in the number of Disability Grant recipients as a direct result of the HIV/AIDS pandemic in South Africa.

Since 2004 the government roll-out of highly active anti-retroviral therapy (HAART) has enabled over 1.6 million HIV-positive persons to have access to medication and to commence antiretroviral therapy (ART) (Nicolay 2008). With improved health status, grant recipients may lose their Disability Grants because their health is restored. The high unemployment rates and inadequate welfare provision for the unemployed in South Africa may present these Disability Grant recipients with a dilemma: taking their antiretroviral medication (ARVs), resulting in better health, or foregoing their treatment in order to keep their CD4 counts low and thus retain their Disability Grant (Natrass 2004).

In South Africa social grants are categorised as follows: Child Support Grant, Care Dependency Grant, Foster Child Grant, Disability Grant, Older Person's Grant, War Veteran's Grant, and a Grant-in-aid (Social Assistance Act No. 13, 2004:6). This study will focus specifically on Disability Grants. Section 9 of the Social Assistance Act No.13, 2004 states that a person is eligible for a Disability Grant, if he or she has (a) "attained the prescribed age" and (b) "is owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession, the means needed to enable him or her to provide for his or her own maintenance".

The purpose of the Disability Grant is to provide a safety net for those who, due to their medical condition, are unable to work; provide financial assistance to those who could not make adequate financial provision for themselves during the period that they were regarded as disabled to work; and assist the persons to provide for their basic needs (Provincial Administration: Western Cape, Department of Social Services and Poverty Alleviation). Circular No.1 of the Provincial Administration (2002) outlines the conditions under which application for a Disability Grant may be made by an HIV-positive individual: a person may apply for a Disability Grant if he/she has reached Stage 3 or 4 of the HIV disease with a CD4 count of below 200 cells/mm<sup>3</sup>. According to this circular, enormous strain is placed on the individual and the State during Stage 4 of HIV/AIDS. During this stage medical costs escalate and jobs are lost. A person who is HIV positive, has reached the age of 18 years and due to his/her disability is incapable of entering the labour market and cannot work may apply for a Disability Grant.

Persons may apply for a permanent Disability Grant for a period of at least 12 months or a temporary Disability Grant lasting not less than 6 months and a maximum of 12 months. Where the person is awarded a temporary Disability Grant, it will be cancelled when the time frame of 6 or 12 months is completed. The person must reapply if his/her condition has not changed. Grants awarded to those classified as permanently disabled may be medically reviewed after 5 years.

A person who has recently been diagnosed as HIV positive does not necessarily qualify for a Disability Grant, even though Section 271 (c) of the South African Constitution provides that everyone has the right of access to “social security, including if they are unable to support themselves and their dependents, appropriate social assistance” (Hardy & Richter 2006:85). Should the person’s general state of health be affected and there are complications, then a person may qualify. If the general state of health is not affected and there are no complications, Disability Grants can be considered at WHO clinical stage 3 or 4, based on clinical information provided by a medical officer.

## 1.2. Setting of the study

Masiphumelele (“we will overcome”) is a stable indigent community of approximately 17,500 residents situated on the outskirts of urban Cape Town, near Kommetjie. It was established in 1992 after a struggle for land rights. The community comprises mainly persons who have migrated from the Eastern Cape since the 1980s, with approximately 90% of adult residents having originally lived in the Eastern Cape. The primary health care clinic in the area was established in 1997. In 2000 the Desmond Tutu HIV Foundation (DTHF) began assisting with the HIV clinic at this facility. The service expanded to become the ARV roll-out site (the Foundation built an additional wing onto the clinic to make this service possible in 2003), rendering preventive services and treatment for persons living with HIV/AIDS (PLWHA), and conducting research into clinical and social aspects of HIV and AIDS (DTHF, Masiphumelele Census 2010, compiled by Dr K. Middelkoop). At the end of January 2011 there were 839 patients receiving ARVs at the clinic, and the DTHF staff members continue to assist with running of the primary HIV service as well (Masiphumelele Clinic Provincial Reporting numbers, compiled by Dr Catherine Orrell.



Figure 1: Aerial view of Masiphumelele from 2010 Census (sourced from ESRI, Redlands, California, USA).

The community profile of this area compiled in 2004 (City of Cape Town: Social Development Directorate 2004) reported low adult literacy; drug addiction; high prevalence of alcoholism and rape; poverty; high rate of unemployment, malnutrition, especially amongst children; and child and sexual abuse. Tuberculosis (TB) and the rates of HIV infection are increasing, and males do not readily accept contraception and family planning. There is basic access to water and sanitation and to electricity in the shacks within plots. Shacks in the Wetlands area, that is, in the informal part of Masiphumelele, have access to communal water and sanitation and unofficial access to electricity through illegal connections from neighbours via extension leads.

At the time of the study, according to statistics compiled by the DTHF data capturing team in 2010, the prevalence of HIV in this community was 26%. Eight hundred and thirty nine people were accessing highly active antiretroviral therapy (HAART), with 80% on first-line therapy and 20% on second-line therapy (Personal communication, Desmond Tutu Director Prof. R. Wood, 2009). This regimen was that followed prior to release of the 2010 treatment guidelines (The South African Antiretroviral Treatment Guidelines 2006).

The following graphs indicate the Masiphumelele Provincial Reporting numbers for 2011, compiled by Dr Catherine Orrell.

Figure 2 represents the total number of patients that commenced ARV treatment since 2003. The 'starting' patients represent those that commenced ARV treatment at Masiphumelele Clinic, while 'transfers in' represent those patients whose ARV treatment was commenced in other provinces or at other healthcare facilities in Cape Town but who are now residing in Masiphumelele.

Figure 3 represents the total number of patients on ARV treatment and the total number of adults remaining in care until the end January 2011.

Figure 4 represents the total number of adult HIV/AIDS deaths, those who were lost to follow up and those transferred out to other provinces or healthcare facilities, until the end of January 2011.

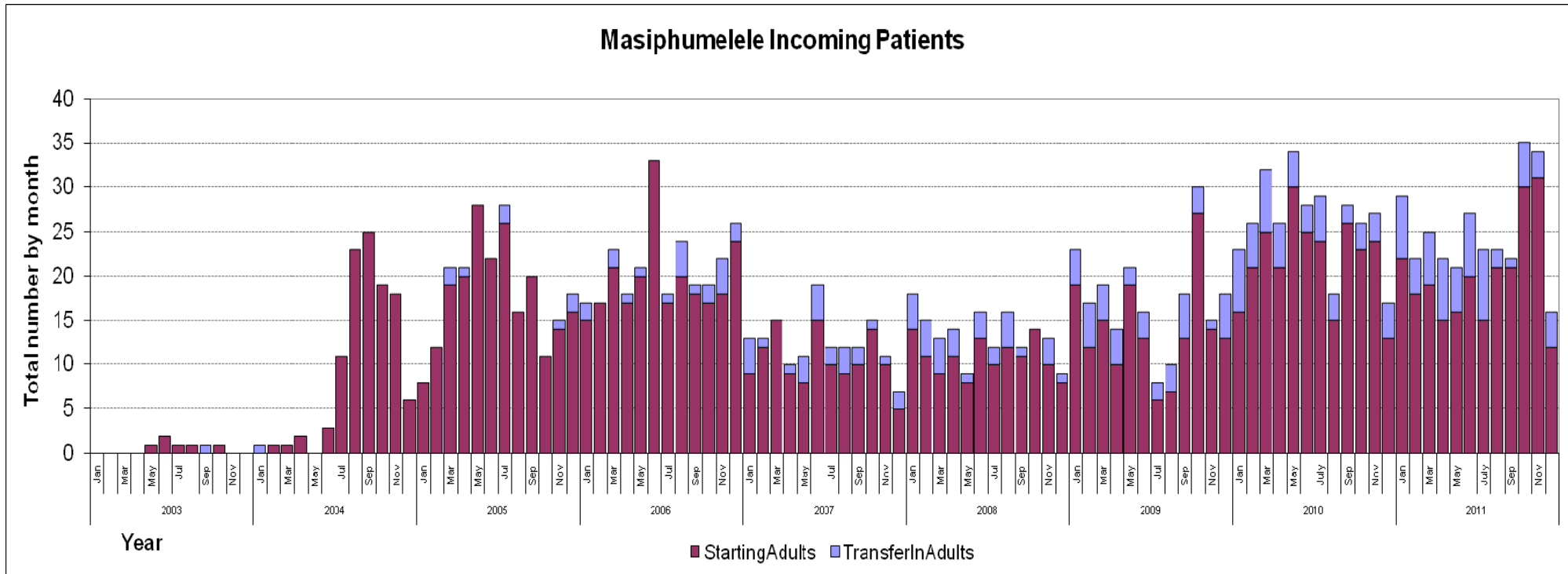


Figure 2: Total number of adults starting HAART, from May 2003 until January 2011 (1276), and total number transferred in during that period (180).

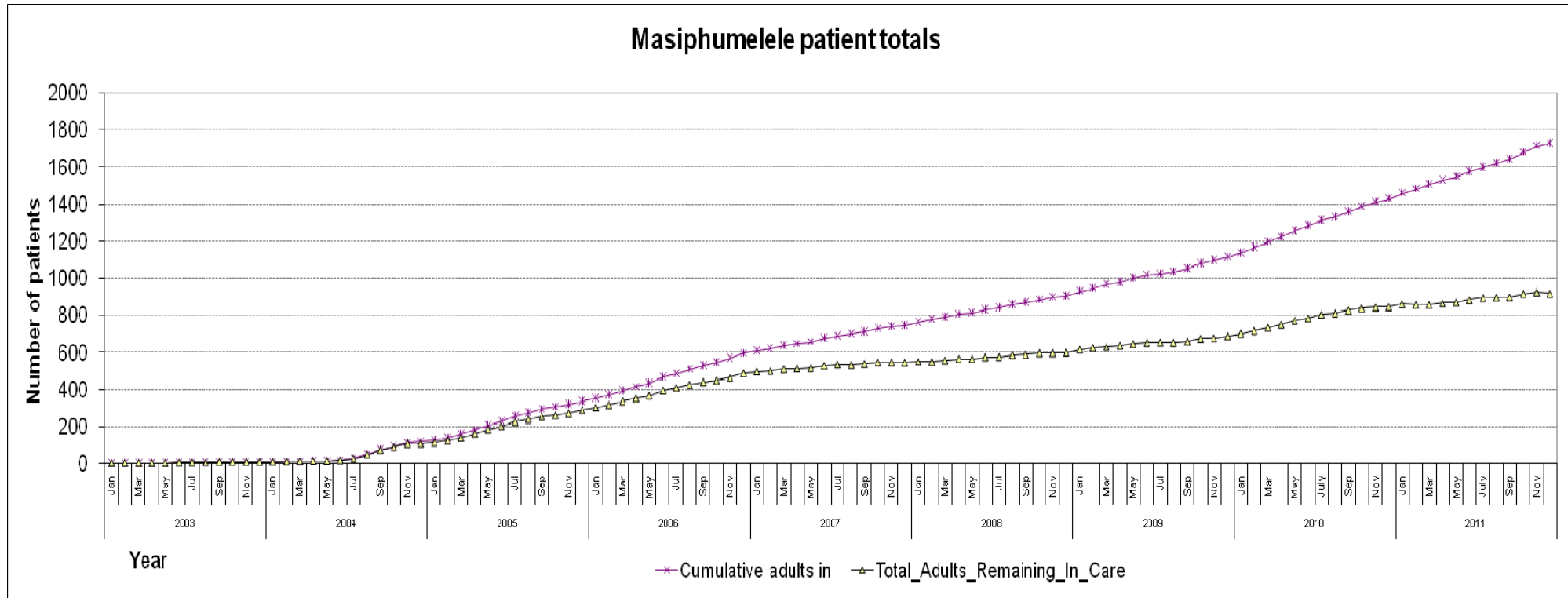


Figure 3: Total number of adults remaining in care at the end of January 2011 (839).

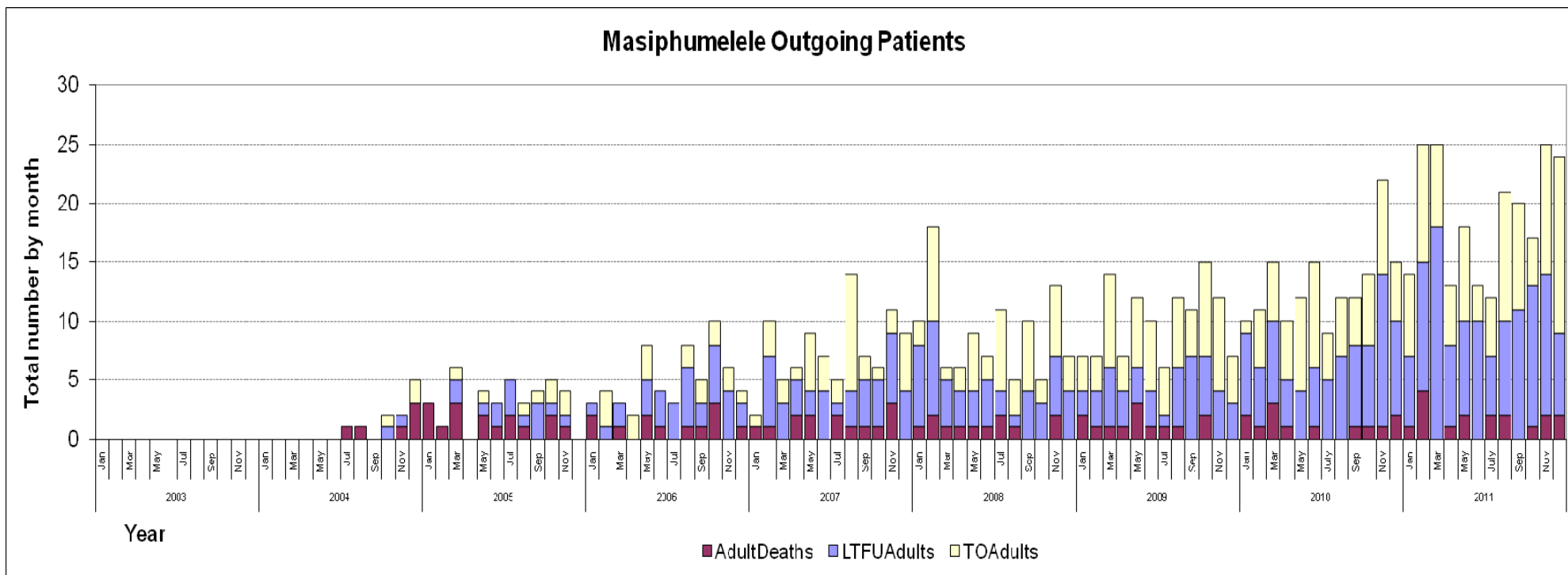


Figure 4: Total number of adult deaths from May 2004 until January 2011 (82), and total number of adults who were lost to follow up (LTFU) during the same period.

For the people of Masiphumelele the burden of unemployment as well as lack of access to employment is very high. In this community the main sources of income are unskilled, casual/informal labour, which means that people do not have the protection of labour legislation. Disability Grants therefore play a part in alleviating the burden of poverty in households which are affected by HIV/AIDS.

### **1.3. Social security structures in South Africa**

South Africa has a well-developed system of social security, seen to be on par with systems in many developed countries (Booyesen & Van der Berg 2005). This system includes a non-contributory pension system as well as a number of social grants aimed at assisting households in caring for children and the disabled (Booyesen 2004). The Social Welfare System in South Africa provides for over 15 million people through seven different grants at a cost of more than R5.03 billion per month. This is equal to 10.8% of government expenditure. While some grants have grown at a predictable rate, Disability Grants have escalated far more rapidly than any other social grant. According to Natrass (2006), the number of Disability Grants for people infected with HIV rose from 27% in 2001 to 41% in 2003, which translates into an average annual growth rate of almost 8% (Booyesen, 2004).

In March 2009 the national total number of social grant beneficiaries was 9 274 593. The number of national permanent Disability Grants was 1 062 816, and temporary Disability Grants 243 007. In the Western Cape Province (15 March 2009) the total number of social grants was 710 853, of which 106 753 were permanent Disability Grants and 33 461 temporary Disability Grants (Department of Social Development of South Africa, daily grant statistics, 15 March 2009). Disability Grants, which have increased to an amount of R1140.00 per month since 2011, constitute a large portion of the social assistance budget.

These grants are critical in protecting the 'vulnerable people', i.e. the sick and disabled. When awarding Disability Grants to persons with HIV/AIDS, most provinces in South Africa use the broad guideline that once a person's CD4 count falls below 200 cells/mm<sup>3</sup>, that person will be eligible for a grant. Usually, once a person with HIV is initiated onto an ARV treatment regimen, his/her CD4 count improves. Since July 2011 all persons with CD4 counts

$\leq 350$  cells/mm<sup>3</sup> have been eligible for ART. The data collection in this study was conducted prior to this ministerial announcement.

John Kruger (Treasury official responsible for welfare), is reported as saying that awarding Disability Grants to HIV-positive persons when their CD4 count drops below 200 cells/mm<sup>3</sup> is a 'very tricky policy area', with which the government is trying to come to grips (*Financial Mail* 2005). According to him, this is a dilemma with which South Africa will be faced for a long time to come. A similar pattern was seen in people with tuberculosis (TB), who would choose to stay sick rather than take medication, in order to be able to continue getting their grant (*Financial Mail* 2005). For policy makers this has created dilemmas which are beyond the scope of this study.

#### **1.4. Development of the rationale for the study**

As a clinical nurse practitioner (CNP) working in Masiphumelele HIV Clinic, I have observed that there appears to be a pattern of HIV-positive persons who are on HAART who become non-adherent, because they are unable to access Disability Grants if their CD4 counts improve. My interest in this phenomenon led to informal enquiries, which seemed to confirm my perceptions. There is limited published information available on this phenomenon and whether continued access to Disability Grants is determined by patients' perceptions of adherence to HAART.

My personal observations over the past four years while working in the community are that poverty and high levels of unemployment within Masiphumelele are the driving force behind HIV-positive persons' non-adherence to medication in order to access Disability Grants. It was therefore important to investigate and explore the perceptions of HIV-positive persons who are becoming non-adherent to ARVs, to determine their perceptions of the value of a Disability Grant within a context of high HIV and AIDS burden.

#### **1.5. Aims and objectives of the study**

The aim of this study was to explore HIV-positive persons' perceptions of the role of/usefulness of Disability Grants and their contribution to health and well-being while on HAART.

## **Objectives**

- To determine perceptions of the purpose and usefulness of Disability Grants among persons who are HIV positive in the Masiphumelele community.
- To explore with participants whether their perception of Disability Grants may affect decision-making with respect to adherence to ARV therapy.

## **1.6. Conclusion**

This chapter provided an introduction and background to the current situation of Disability Grants and HIV persons on antiretroviral treatment (ART) in South Africa, and in the area where the research was conducted. A brief overview of the different social grants available and the social security structure in South Africa was given, as well as of the development of the rationale for the study and the aims and objectives.

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## **Chapter 2**

### **Literature review**

#### **2.1. Introduction**

In the field of HIV/AIDS and non-adherence to HAART, my focus in this literature review is on the access to, usage and impact of Disability Grants for people who are HIV positive and, secondly, on what helps or hinders adherence to ARV medications. There is a large body of literature on HIV/AIDS, poverty, and the socio-economic impact of HIV/AIDS. This review has been limited to the socio-economic effect of HIV/AIDS on poor households in South Africa and Disability Grants and their role in HAART.

For this study the following databases were searched over the period 2001-2011: EBSCO HOST, Science-Direct, Google Scholar, Biblioline, CINAHL, MEDLINE, Academic Search Premier, Soc Index with full text, Health Source: Nursing/Academic Edition and Africanline. To conduct the literature search the following keywords were used: HIV/AIDS, Disability Grants, HAART, poverty and unemployment. This review has been structured under the following themes: HIV in South Africa and the ARV roll-out; socio-economic effects of HIV/AIDS on poor households; HIV/AIDS and employment; poverty and HIV/AIDS; role of social grants in poverty alleviation; and Disability Grants and their role in HAART.

#### **2.2. HIV in South Africa and the ARV roll-out**

South Africa has one of the worst HIV/AIDS epidemics in the world. The total prevalence rate of HIV/AIDS in South Africa is estimated to be 12 - 20% for adults between the ages of 20 and 64 years (Nicolay 2008). The prevalence rates for HIV vary according to province, race and ethnicity (Kenyon et al. 2009), and age, gender, urban or rural location (Karim et al. 2011; Batzing-Feigenbaum et al. 2007), among other factors. The HIV prevalence rate for adults (aged 20-64 years) is 20%, and appears to be stabilising as survival by accessing ART increases (Karim et al. 2011; Lane et al. 2011). There are an estimated 5.7 million South Africans who are HIV positive, the largest number of any country in the world. HIV/AIDS and associated opportunistic infections are the leading cause of death in South Africa. An

estimated 2.692 million people had died due to AIDS-related illness by the end of 2008 in South Africa, equating to 1412 per day (Nicolay 2008), the largest number of any country in the world. Every day 1068 new infections occur (Nicolay 2008), although there was a decline in the number of new HIV infections over the period 2002-2008, as reported by Rehle et al. (2010).

International initiatives such as the US President's Emergency Plan for AIDS relief (PEPFAR) and the United Nations Global Fund to Fight AIDS, Tuberculosis and Malaria have increased access to HAART in South Africa (Nachega et al. 2006). The implementation of the comprehensive HIV and AIDS care, management and treatment programme, which provides HAART at no cost through the public health services sector, started in the first quarter of 2004 (Nachega et al. 2006).

From a historical perspective the progressive AIDS Plan resulted from a series of consultative meetings at the National AIDS Convention of South Africa in 1992, and was then adopted by the New Government of National Unity in 1994. HIV/AIDS was not to be prioritised by the New Government of National Unity, because the AIDS programme was placed in the Ministry of Health, rather than in the President's office.

There was initial government opposition to the use of ARVs for either prevention or treatment, and this became entrenched during the period of AIDS denialism, during the presidential term of President Thabo Mbeki (1999-2008). South Africa encountered many challenges in the quest to roll-out ARVs, including the HIV/AIDS denialism phase mentioned here. This denialism approach of the former president and former Minister of Health Manto Tshabalala-Msimang offered false hope to many PLWHA as they were reported to be sceptical of the causation of AIDS and the harmful effects of ARVs (Kalichman, Eaton & Cherry, 2010). After repeated episodes of denialism President Mbeki was asked in October 2000 to withdraw from public comment on AIDS. Former Health Minister Tshabalala-Msimang then took the agenda forward by continuing to resist the introduction of the Prevention of Mother-to-Child Transmission (PMTCT) programme, until she was forced to yield by a Constitutional Court ruling. She also resisted the introduction of HAART for AIDS-sick people, until a Cabinet revolt in late 2003 also forced her to back down (Ndinga-Muvumba & Pharoah 2008). In 2006 the new Deputy Health Minister spoke out in favour of HAART, and this resulted in a new 'National Strategic Plan' to cut HIV

infection in half and to increase HAART coverage to 80% by 2011 (Ndinga-Muvumba & Pharoah 2008).

Combination therapy has been proved to be effective in the reduction of AIDS-related morbidity and mortality. Specialist physicians in industrialised resource-rich countries with a relatively contained HIV/AIDS epidemic are responsible for ARV management. In sub-Saharan Africa, however, with over 22.4 million people living with HIV and 3 million in need of urgent treatment, it is not possible to have specialist physicians providing care for treatment of HIV/AIDS patients. With the scale-up of ARVs in South Africa since 2004, this has highlighted the human resource challenge of delivering and sustaining the ARV roll-out programme (Van Damme, Kober & Kegels 2008).

In 2006 the World Health Organization (WHO) proposed task-shifting as a method to meet the Millennium Development Goals, because there were 57 countries facing critical shortages of health workers (WHO 2007a, 2007b). Thirty six of these countries were in sub-Saharan Africa, and this situation has resulted in a human resource crisis. Task-shifting can be defined as “the delegation of medical and health service duties from higher to lower cadres or new cadres as well as a coping mechanism for general and specific human resource shortages” (Zachariah et al. 2008:549). The emigration of trained professionals, difficult working conditions, poor salaries, low motivation and a high burden of HIV/AIDS has left South Africa with 27 doctors per 100 000 members of the population, which is higher than in other sub-Saharan countries, but still too few for the growing pandemic of HIV/AIDS (Zachariah et al. 2008). Even though task-shifting has met with challenges (for example, nurses having resisted taking on doctors’ roles without salary increases (Zachariah et al. 2008), it has gained momentum with the release of specific guidelines and recommendations by the WHO.

Studies comparing nurse-managed ART versus doctor-managed ART conducted by Sanne et al. (2010) in South Africa, Shumbusho et al. (2009) in Rwanda and Philips, Zachariah and Venis (2008) in Malawi, showed that nurse-monitored therapy was not inferior to doctor-monitored therapy. These findings demonstrated the successful use of task-shifting in HIV/AIDS care in resource-limited and resource-rich (the UK) countries. From these studies there is evidence that resource-poor countries can achieve targets for universal access to life-saving ARVs, and sustain this life-saving intervention without compromising the quality of care for persons with HIV/AIDS.

Task-shifting is seen as vital in scaling-up treatment access, while making the best of available resources (Philips et al. 2008). Task-shifting requires participation and involvement by clinic staff and all levels of primary care management for effective and sustainable interventions (Uebel et al. 2011). Task-shifting has the potential to increase the access points to treatment and care tremendously, and hereby reduce ‘bottlenecks’ in the system caused by a lack of staff able to perform key tasks.

The above studies have demonstrated that task-shifting is successful using appropriately trained nurses to monitor ART care and support. Morris et al. (2009) demonstrated in a Zambian study that task-shifting was successful in improving access to ART, but longer-term solutions are necessary to effectively manage the human resource crisis.

### **2.3. Socio-economic effects of HIV/AIDS on poor households**

In the context of the socio-economic effects of HIV/AIDS on poor households, similar trends have been found internationally, in sub-Saharan Africa and in South Africa.

#### **2.3.1. International trends**

Internationally, socio-economic effects of the HIV pandemic have been reported from resource-poor as well as resource-rich countries. A study conducted by Mahal and Rao in India (2005:582-586) reported that there is an immediate impact on earnings and income of households with members with HIV/AIDS, because these individuals are in their most productive years, are members of the labour force, and are in a position to provide support. The impact takes the form of loss of earnings when the individuals become sick or die prematurely as a result of HIV/AIDS.

HIV-affected households faced growing economic hardships because the average monthly expenditure on food and treatment increased substantially, and the income declined by as much as one-third. Lost life-time earnings due to an AIDS death were estimated to be 10 times the annual treatment costs of AIDS. Income and earnings were also affected by the loss of jobs from stigma associated with HIV infection, even though the HIV-positive individual was not sick. In this instance the loss of earnings was even greater. A large proportion of the family’s income was used on treatment costs, and when the individual died the household

was faced with adverse economic consequences of losing their breadwinner. After losing the breadwinner the household had to compromise on the children's education by withdrawing them from school and sending them to work. AIDS deaths in a household were associated with declines in nutrition, loss of health care and loss of educational continuity among children as a result of minimal safety nets provided by the public sector.

A study conducted by Xu et al. (2007:791) in Eastern China reported that a large proportion of the family's income was used on treatment costs. Ill patients also depended on family members to care for them. Family members were then unable to look for better-paid work in the city, leaving most households in poverty.

The economic impact of HIV/AIDS has also been reported in middle-income countries. An Australian study found that PLWHA were at an economic disadvantage, with 26.9% of the sample studied living below the poverty line. Over half of the sample used government benefits as their main source of income (Grierson, Pitts & Thorpe 2007:623).

### **2.3.2. Impact in sub-Saharan Africa**

The socio-economic impact of HIV/AIDS varies from country to country, but has been greatest in sub-Saharan Africa. The two major economic effects of HIV/AIDS are the reduction in labour supply and increased costs in household expenditure when a household member becomes HIV/AIDS infected. A reduction in labour supply means that those persons who are employed or who have the potential of becoming employed are now infected with HIV. There is the loss of young adults in their most productive and parenting years, with a devastating effect on the livelihoods of affected households and direct costs for expenditures like medical care, drugs or funeral expenses when employed household members become sick or die (Piot, Greener & Russell 2007:314). More than 16 million children under the age of 18 years have been orphaned around the world, and around 14.8 million of these children live in sub-Saharan Africa (Piot et al. 2007:314).

A study conducted by Oluwagbemiga (2007:669-675) in Nigeria found that HIV/AIDS had severe economic impacts in areas or countries where the prevalence is high. In this study in-depth interviews were conducted to collect information from 188 PLWHA through support groups in the state, while four focus group discussions were conducted with people affected

by AIDS. At the household level, HIV infection or death was found to affect the family's access to resources, with the economic effects first felt by individuals and their families. The transition from relative wealth to relative poverty within affected households was rapid. Parents and grandparents took on the responsibility for rearing the children of the infected persons and the orphans of those who had died from AIDS-related illnesses. Some of these grandparents could not afford to meet the requirements of these children, and resorted to borrowing in order to feed the children. Some HIV-infected people had to sell their properties to enable them to cope with the economic effects of the virus, while their children had to leave school because they could not afford to pay school fees.

HIV/AIDS also had an impact on the extended family, as they had to take on the responsibility of caring for the children. The harsh economic conditions in Nigeria this country made it difficult for relatives to provide the traditional safety net needed by the children of people affected by HIV/AIDS. This led to a decline in school enrolment, as children had to drop out of school to take care of parents or family members or were unable to afford school fees owing to the death of their parents. HIV/AIDS led to increased dependency within communities, and when the family member died other members were severely affected because their entire savings and assets were completely spent before the onset of the disease, leaving survivors destitute. Most of the households in the study were headed by AIDS widows with dependent children, and this pushed them further into poverty. Due to stigmatisation, their main safety net of assistance from other family members and the community was non-existent (Oluwagbemiga, 2007:669-675).

Tekola et al. (2008:995-1000) conducted a cross-sectional study in Addis Ababa, Ethiopia. They reported that relatives or primary caregivers of deceased adults experienced financial difficulties within households following the death of a household member due to an AIDS or non-AIDS death. Reasons cited for the decline were the loss of a productive household member and/or other direct or indirect costs related to illness and death. The death of an adult member in a household of lower socio-economic status leads to great difficulty in coping with the loss of a productive adult. This was more evident when the deceased was male or middle-aged, because such persons were often the main breadwinner of the household. The loss of lifetime earnings due to an AIDS death had a detrimental effect on households because of the number of productive years lost (about 27 years). This contributed to a large

difference in indirect costs between AIDS and non-AIDS deaths (Tekola et al. 2008:995-1000).

Floyd et al. (2008:526-529) conducted a population-based survey in the 1980s and conducted the retrospective cohort study from 1998 to 2000 in Northern Malawi. One hundred and ninety seven HIV-positive and 396 HIV-negative individuals were identified and compared in terms of long-term social and economic impacts on the spouses of HIV-infected individuals. They reported that by the end of 2000, 26% of the wives of HIV-positive individuals were widowed, compared to only 5% of wives whose husbands were HIV-negative. Household dissolution was high among widows of HIV-positive men, as these women were less likely to remarry and were household heads, which is not the norm in Malawi. The widows of HIV-positive men had very little household assets, no inheritance, and had difficulty in accessing education, land, livestock, health care, credit and extension services, putting them at a financial disadvantage. Death of an HIV-positive adult had severe consequences, including dissolution of the household if the person had been as the breadwinner or household head. Due to financial difficulties and a struggle to survive, most of the children of widowed HIV-positive individuals were not co-residing with their mothers, but were cared for by a close relative.

Seeley et al. (2008:1438-1445) conducted an in-depth longitudinal study with 26 households in rural Uganda. They reported that those households affected by the death of an adult household member as a result of HIV/AIDS were worse off financially. Most of the children whose parents died as a result of HIV/AIDS were living with their grandmothers or being fostered by relatives. However, instead of some of these households dissolving completely as a result of an AIDS-related death, many household members established new households, finding new ways to sustain their families. There were a few households which were unable to rise out of their poverty-stricken situation. Household finances were drained when some households had to help another to survive.

### **2.3.3. The effects in South Africa**

The HIV/AIDS epidemic has resulted in a socio-economic crisis in South Africa. The economic security of households has diminished and this has become problematic, especially for black African households in South Africa, as the majority African population in South Africa has the highest rate of unemployment, lowest per capita income and highest HIV prevalence rates of all racial groups (Natrass, 2004:2). In December 2010 South Africa's official unemployment rate was 24% (Statistics South Africa 2010). The unemployment rate for black South Africans was 28.1%, for coloureds 21.3%, for Indians/Asians 7.9%, and for whites 5.5% (Statistics South Africa 2010).

South Africa's HIV/AIDS epidemic coincided with a time period in which the unemployment rate was high and rising, with limited social insurance available for unemployed adults of working age. This resulted in loss of employment as well as failure to find new employment, which had a catastrophic effect on household living expenses. Households without wage-earners were forced to rely on money from friends or relatives living elsewhere, on parents' old-age pensions, on the Child Support Grant and the Disability Grant (Natrass 2004). AIDS-related morbidity remains high, and this occurs within the context of widespread poverty and inequality, with many South African households reporting food poverty, and with higher rates in rural, larger and lower-income households (Naidu & Harris 2006). Despite the increasing access to ARVs, access is not yet equitable across the country (Scott et al. 2005), and requires increased resource input from the public sector and creative approaches to implementation of decentralised ARV programmes (Bedelu et al. 2007).

HIV/AIDS can have a severe impact on households infected and affected by the virus. It is often the poorest of society and the most vulnerable who suffer severe consequences. In many cases, having an HIV/AIDS member within the household can cause the household to disintegrate. Parents die and children are sent to grandparents or relatives for care and upbringing. HIV/AIDS individuals who provide a household income are now prevented from working because they are either too ill to work, are caring for another sick family member, or are unable to find employment. This can have a 'domino effect' on every other member in the household, because children may be forced to abandon their education to care for ill parents, have to head households due to the death of one or both parents, as well as dramatically

increasing the numbers of orphans, particularly in high prevalence countries such as South Africa (Piot et al. 2007:316).

The number of orphans alive at the end of 2009 in South Africa was 1.9 million, and South Africa is predicted to have 2.3 million children orphaned by AIDS by 2020 (Cluver, Gardner & Operario 2007). Orphans may be a particularly vulnerable group (Cluver et al. 2007), and are more likely to live in female-headed households where more people are dependent on fewer income earners, putting extra pressure on AIDS orphans to contribute financially to the household and driving these children to the street to work or beg for food. They are at increased risk of mental health problems (Cluver et al. 2007). The economic effects of HIV/AIDS will first be felt by individuals and their families and then spread to firms, businesses and the macro-economy (Piot et al. 2007).

Adult mortality (among those aged 20-64 years) in South Africa at the end of 2008, based on death certificates, showed a dramatic increase, largely due to AIDS-related deaths. AIDS deaths have caused major social and economic disruptions. The socio-economic impacts of HIV/AIDS appear to be greater on the poor, powerless and marginalised, leading to financial, resource and income impoverishment. In South Africa the tragic and untimely loss of a parent and productive citizen has not only affected families, but also farms and other workplaces, schools, health systems and governments, touching almost every aspect of life (Ashford, 2006:2; Piot et al. 2007:4).

The economic impact usually begins as soon as the member of the household starts to suffer from HIV-related illnesses. Examples of these impacts include loss of income of the person who is frequently the breadwinner, substantial increase in household expenses, and increased responsibility of other members of the household (usually daughters or wives) who may miss school or work less in order to care for the sick person. The death of the person, particularly if the main breadwinner, results in permanently reduced or total loss of income, as well as funeral and mourning costs. Children may be removed from school in order to save on educational expenses and increase household labour, resulting in a severe loss of future earning potential (Veenstra & Whiteside 2005). Poverty will be increased, and this in turn contributes to the increase of the spread of the epidemic. Income inequality usually increases with poverty as well as with the mobility of people when they leave their homes in search of employment (Veenstra & Whiteside 2005:198).

HIV/AIDS affects the labour within the household, as illness and death from AIDS causes depletion of the resources of a household. The family will experience reduced income when the breadwinner is unable to continue working; the more vital the role that the person has in earning the family's income, the more severe the consequences. This reduced income is often paired with a significant increase in expenditure (Isaksen, Songstad & Spissoy 2002).

HIV/AIDS has a damaging effect on poor households in South Africa, sending them from poverty into destitution (Chhagan et al. 2008:96-104). HIV/AIDS contributes to the decrease in income as well as compromising the health of individuals, resulting in a decrease in expenditure on basic needs. There is also shrinkage and reallocation of the household budget in PLWHA. This has the effect of reducing food security in an affected household, which in turn increases the risk of malnutrition and sickness of other household members.

HIV affects the health and wealth of households, aggravating pre-existing poverty (Bachmann & Booysen 2004:818-825). Booysen (2004:45-55) reported that the incidence, depth and severity of poverty was worse among HIV-affected households in South Africa compared with non-HIV-infected or affected households that had not experienced morbidity and mortality. HIV-affected households were poorer, more dependent on non-employment sources of income, and spent less money on food. Household expenditure decreased more rapidly in HIV-affected households as the PLWHA became more ill, could not perform normal tasks and were more likely to be admitted to hospital. Booysen and Van der Berg (2005) found that HIV/AIDS resulted in a vicious cycle of poverty and disease. They reported that adult members became ill and were forced to give up their jobs, resulting in a decrease in household income. HIV/AIDS therefore pushes households towards or further into poverty, because PLWHA have limited access to employment and are more vulnerable to HIV infection because they are poor.

Naidu and Harris (2006:417-424) reported that HIV/AIDS affected household income and expenditure in four ways, namely: temporarily as a result of absence from work by an HIV-infected worker; temporarily and possibly permanently through the loss of earnings of caregivers; permanently when household income that had been temporarily increased through a disability pension granted to a person with HIV/AIDS ceased at that person's death; and permanently through loss of employment as a result of sickness and death.

Important survival strategies identified in this study were the continuation of the sick member

working as long as possible, borrowing money from friends and relatives, receiving transfers (food and clothing) from relatives, and taking up social grants. The uptake of grants by eligible households was higher among HIV-affected than HIV-non-affected households. Disability Grants were only available to those who produced a medical report stating that the individual was unable to provide a livelihood. The Child Care Grant was available to children in these households who qualified, but does not replace the Disability Grant as the family may already be receiving the Child Care Grant.

Findings by Hosegood et al. (2007:1259-1248), which are consistent with those of Booysen and Van der Berg (2005) and Ganyaza-Twalo and Seager (2005), revealed that predominantly poor households face insecurity in many aspects of their lives and adverse consequences of multiple experiences of HIV/AIDS, and had many social and emotional repercussions when their households were affected. Most households in the study were headed by pensioners, who were put under severe strain as repeated deaths of younger adult members who had moved back home due to their illness increased the dependency ratio of households. Economic resources of households experiencing repeated episodes of illness and death were severely affected, because increases in expenditure on health care and funerals often coincided with losing the income from the patient or carer, resulting in financial difficulties. Affected households battled to afford health care, schooling or adequate food, and often resorted to borrowing money.

Children (orphans) were taken out of school to live with other households. Households also had difficulty in obtaining government cash grants for disability and caring for orphans. Grant applications were delayed because sometimes the poorest households did not have enough transport money to get to health and welfare offices, and in some cases had to pay the bribes demanded in order to supply documents or process applications. Furthermore, respondents were stigmatised and discriminated against because of their association with HIV/AIDS deaths and felt more isolated, deterring people from visiting or helping them out; in this way poverty exacerbated the stigma around HIV/AIDS. With no other income or assistance, many households entered a very bleak period, unable to buy sufficient food or pay for school fees. However, all households reaching this extreme situation during the study received financial assistance through government Foster Care or Child Support Grants (Hosegood et al. 2007:1259-1248). This study highlighted the fact that households are not isolated from events occurring in their immediate social networks or elsewhere in the

community, because adult deaths in one household have a detrimental effect on others connected to it.

As has been shown, similar trends with respect to the socio-economic effects of HIV/AIDS on poor households have been reported internationally, in sub-Saharan Africa and in South Africa. Results from these studies indicate that poorer households experience a greater decline in socio-economic status following the death of a household member, and that AIDS mortality has more detrimental effects on household economic status than deaths due to other causes exceeding those of a non-AIDS death by 58% (Hosegood et al. 2007:1259-1248). AIDS deaths were also highest among poor households than those that were better off, because poor households became more impoverished as a result of death.

#### **2.3.4. Effects on food and nutrition**

More than 800 million people remain chronically undernourished on a global level (Ivers et al. 2009:1096-1100). With more than 33.2 million people living with HIV/AIDS, this largely overlaps with a population already experiencing low diet quality and quantity (Ladzani, 2009). Ivers et al. (2009) reported that as a result of malnutrition, morbidity and mortality of PLWHA in developing countries is still unacceptably high, despite advances in HIV/AIDS care and treatment with excellent clinical outcomes. PLWHA face not only illness, but also impaired productivity, declining income and difficult choices among essential but competing expenses such as 'food versus health care' and 'schooling versus rent'. The physiological complications of the progression of HIV/AIDS are also combined with problems of poverty, that contribute to insufficient consumption of adequate quality and quantity nutrition to boost the immune system and support medical therapy. Food insecurity is defined as "a persistent lack to adequate food in needed quantity and quality", and HIV/AIDS now overlaps this, with dire consequences (Ivers et al. 2009:1094). The Food and Agriculture Organisation of the United Nations further defines food security as "a situation in which all people have, at all times, physical, social and economic access to sufficient, safe and nutritious food to satisfy their physiological needs to customary food preferences and to guarantee them an active and healthy life" (Federal Ministry for Economic and Cooperation Development 2008:1).

Undernutrition has a negative impact on PLWHA, resulting in poor resilience of individuals, households and communities which in turn will affect their clinical, nutritional, quality-of-life and economic state (Ivers et al. 2009). A lack of food at household level can lead to risky

coping strategies such as ‘sale of assets’, ‘redirection of wage/labour’ or ‘exchange of sex for money or food’, in turn increasing exposure to HIV/AIDS as well as economic vulnerability, since it is difficult to take HAART on an empty stomach (Ivers et al. 2009). Gillespie (2008) also reported that food insecurity may increase exposure to HIV, especially in women (who seem more vulnerable), because women and girls may engage in transactional sex in order to generate an income to feed their families. The overall loss of productivity due to HIV/AIDS contributes significantly to hunger and poverty in households, families and communities, resulting in undernutrition which in turn complicates the fight against HIV/AIDS.

#### **2.4. HIV/AIDS and employment**

The HIV/AIDS pandemic has brought with it a reduction in population growth, mainly since it has affected persons in the prime, working phases of life. This has influenced the rate of economic growth, resulting in changes in the framework of employment as one of the primary hallmarks of the HIV/AIDS pandemic (Arndt & Lewis 2001).

In the pre-HAART era, employers were hard hit by a loss of workers, absenteeism, rising costs of providing healthcare benefits (including expensive HAART) and payment of death benefits (Ashford 2006). In the post- HAART era in South Africa, Rosen et al. (2010) found that there are some positive economic and social advantages anticipated as a result of large-scale treatment provision, such as increases in workplace participation, productivity and the ability of PLWHA to carry on normal lives. The high unemployment rate in South Africa, with 4.1 million people unemployed (Rosen et al., 2010), has meant that PLWHA have to compete with healthy work seekers and struggle to find employment.

#### **2.5. Poverty and HIV/AIDS**

There is a strong link between poverty and HIV/AIDS infection in Africa, because poor people are biologically more vulnerable to HIV/AIDS as a result of lowered immunity and malnutrition. This is a well-established link and, according to Stillwaggon (2002), the poor have fewer resources to deal with chronic and ultimately deadly illnesses. Due to biomedical reasons poor people, are more vulnerable to malnutrition and parasitic infections, and more

likely to become infected with HIV, because they are hardest hit by infectious diseases. Poorer people also have less access to an adequate education and income, putting them at a higher risk of contracting HIV/AIDS (Nattrass 2006). According to Ganyaza-Twalo and Seager (2005) poverty presents a risk factors to human and financial resources, such as low levels of education, low levels of literacy, few marketable skills, generally poor health status and low labour productivity. Ganyaza-Twalo and Seager (2005) further describe the link between HIV and poverty at household level, where households affected by HIV felt the impact of extreme poverty, making it impossible for them to resume normal functioning.

Shisana et al. (2010:43) reported that “national data suggest that there is an increasing link to HIV and poverty, especially in South Africa and that it is rife in the poor informal settlements that are hard hit by HIV and not the rich”, because poor people are more biologically vulnerable to disease. HIV and poverty are closely linked, because PLWHA may indulge in risky behaviour as a means of survival. This statement in turn is consistent with the 26% prevalence of HIV in the Masiphumelele community, which is linked to the high unemployment rate and low literacy level, as well as the area being an informal settlement.

## **2.6. Role of social grants in poverty alleviation**

The South African Government of National Unity in 1994 made a commitment to set specific goals within the context of social policy. The South African social security system has been described as one of the largest anti-poverty instruments in the post-apartheid years (Lalthapersad-Pillay 2008). The social policy aims at eliminating poverty, achieving an acceptable distribution of income, lowering unemployment levels and increasing social assistance programmes. In this way social welfare transfer to households has increased significantly, as has the number of people eligible for grants, since there was a clear decision to increase welfare spending both in terms of value of grants paid and scope of coverage (Pauw & Mncube 2007).

Eradicating poverty was the highest priority for the government, and the programme aimed to improve the lives of all South Africans; the goal set was to do this between 2004 and 2014. A document entitled *The Anti-poverty Strategy* was released by President Jacob Zuma to assist in eradicating poverty (May, 2010). The nine pillars of this strategy are creation of economic

opportunities; investment in human capital; income security; basic services and other non-financial transfers; improving health care; access to assets; social inclusion and social capital initiatives; environmental sustainability; and good governance (May, 2010). Since 2002 strong overall income growth, including the expansion of social grants, has resulted in a decreased risk of income of the poorest 20% of the population. The rate of income improvement among the poor was not matched to that of the rich, and while income poverty is declining, inequality has not been reduced (Pauw & Mncube 2007).

The South African Government provides several social support grants to its citizens in need, including the Disability Grants for which HIV/AIDS positive persons can apply. Government social grants have become integral for survival to many families. For the very poor families the grant can account for the average monthly income. It is used to support entire families, and studies conducted by Hosegood et al. (2007), Booysen (2004) and (Naidu & Harris 2006) have shown that when households have access to social grants, they are more likely to work their way out of poverty. Social grants therefore play an important role in alleviating the socio-economic impact of HIV/AIDS, in particular in keeping affected households from slipping deeper into poverty (Booyesen & Van der Berg 2005). Social grants have also been shown to have had a considerable impact on decreasing the numbers of people who are living in poverty. Disability Grants, which form a large component of social grants relative to the average income levels of the poor, therefore play an important role in supporting poor affected households. Booysen and Van der Berg (2005) reported that half of the households that lost access to social grants could not afford basic foodstuffs or were struggling to make ends meet financially. They reported that the greater the degree of poverty, the more likely it is that grants will hold a greater benefit for potential beneficiaries. Social grants are often spent on food.

## **2.7. Disability Grants and their role in HAART**

Stopping HAART in order to access a Disability Grant is a serious issue, since it contributes to the development of treatment resistance. Hardy and Richter (2006) raised a concern that the loss of a Disability Grant may either discourage PLWHA from commencing treatment or encourage them to interrupt HAART so that they can access a Disability Grant. With the public health sector ARV roll-out programme that started in 2004, PLWHA now have access

to life-saving treatment. PLWHA are now becoming well – and are in danger of losing their Disability Grants, often the only source of income to provide for basic services and food, not only for them but also for their extended families.

Currently South Africa has seven first-line and one second-line therapy drugs available. Regimen 1 is the first choice of treatment, and regimen 2 offered for treatment failure or specific side-effects, which is boosted with a protease inhibitor (Appendix F). There is a salvage regimen available, but only on specialist referral, and it is not cost-effective. The optimal adherence percentage for virological suppression is 95%. In a prospective cohort study conducted by El-Khatib et al. (2011:3-11) in Johannesburg on women in their first 24 weeks on ARVs, they reported that when adherence levels dropped below 80%, only then was there an association with virological failure. Virological failure was evident in the overall group of women who had single-dose nevirapine, and they were at a greater risk of virological failure if their adherence was less than 95%.

With the initial roll-out of ARV programme in 2004 the programme consisted mainly of unboosted protease inhibitors requiring > 95% adherence to ensure virological suppression. Currently, with non-nucleoside reverse transcriptase inhibitors (NNRTI) and boosted protease inhibitor regimens, an adherence level of 70-90% may be adequate to achieve virological suppression (El-Khatib et al. 2011). However, for optimal outcomes and to avoid disease progression, a maximum level of adherence of 100% should always be recommended to people receiving ARVs to prevent virological failure. Achieving viral suppression therefore requires excellent ARV adherence, which is the most important determinant of survival for PLWHA in the HAART era. Therefore, when persons with HIV/AIDS fail to adhere to their ARV regimen, they will fail to maintain viral suppression, resulting in a vicious cycle of the emergence of drug resistance and increasingly complex treatment regimens, which will further frustrate HIV/AIDS-positive persons – and then more drug resistance will emerge, as reported by Lucas (2005) and Orrell (2004).

In a workshop conducted by the AIDS Law Project, Hardy and Richter (2006) reported that the current South African social security system is based on the assumption that the majority of adults will be able to adequately support themselves and their dependents. State social security is only available to 'special groups', meaning physically and mentally challenged persons who cannot care for themselves. Hardy and Richter (2006) reported that the social

security system is inadequate in a society with widespread poverty and unemployment, as well as grant recipients utilising the grant to support their immediate and extended families. Disability Grant funding is usually supposed to support good nutrition and transport to and from the clinic in the absence of a salary or any other type of social security for working age adults, but for almost all HIV/AIDS-positive persons receiving a grant, this has become a “poverty alleviation grant”. Hardy and Richter (2006) found this ironic, because when HAART is taken, HIV/AIDS persons’ immune systems recover, pushing their CD4 counts back above the Disability Grant threshold of 200 cells/mm<sup>3</sup>. They then risk losing the very support that allowed them to make a recovery in the first place.

HIV/AIDS is also undermining the economic security of most affected households. Hardy and Richter (2006) argued that the Disability Grant is one way in which poor households can access social security. Disability Grants serve as a lifeline to poor AIDS-affected households, to the extent that lower household income translates into lower food expenditure and may affect the status of people on HAART. PLWHA, as their health improves on ART, may be faced with the choice between income and health.

Nattrass (2006) and Simchowitz (2004) found that the CD4 count to date has proved to be unreliable to a large extent in determining the capabilities of PLWHA. Most PLWHA preferred to stay on treatment and also to keep their Disability Grants, because it provided food security for them and their families. Therefore stopping their Disability Grant on the basis of improved CD4 count may expose not only the PLWHA but also their families to hunger and poverty. The ARV roll-out now complicates receiving the Disability Grant, because once the health of the PLWHA is improved, they may no longer qualify for a grant. Those that discontinue HAART long enough to get their grants reinstated will not only undermine their health, but also contribute to resistant strains of viruses. Therefore temporary Disability Grants should not use CD4 cell counts, which are helpful for monitoring diseases but are an unreliable indication of functional ability. The implication is that Disability Grants reverse the gains and directly lower the quality of life for PLWHA.

Phaswana-Mafuya, Peltzer and Petros (2009:533-545) reported that all stakeholders in the Eastern Cape supported the Disability Grant because it improved the lifestyle of PLWHA. Data were elicited from a cross-sectional explorative qualitative/quantitative study conducted in the Eastern Cape of South Africa. The qualitative component of this study involved 38

HIV/AIDS stakeholders using a semi-structured interview process. The quantitative component involved 607 PLWHA who were interviewed using a structured questionnaire. They based their view on the fact that although apartheid has ended in South Africa, severe poverty and high socio-economic inequality still remain a big challenge for the State, especially among the previously disadvantaged groups. Social grants such as the Disability Grant are still recognised by the government as the most effective way to alleviate poverty, which to date is their highest priority.

Even though the Disability Grant may alleviate poverty it still hinders positive prospects of ARV treatment, because some people will forgo their treatment to access the Disability Grant. The study showed that Disability Grants act as a lifeline for most PLWHA, providing them with food for more than 12 months as well as for their families, in comparison to those PLWHA not receiving a grant. The study also showed that the Disability Grant was used to meet basic household needs like food, clothing, school fees, settling debts and healthcare needs. Four in five PLWHA indicated that Disability Grants helped them in caring for ill household members as well as improving household health. More than half the stakeholders in the telephonic interview indicated that the CD4 count ( $<200$  cells/mm<sup>3</sup>) was used as the main criterion for putting PLWHA on a Disability Grant. According to the 38 HIV/AIDS stakeholders this can be problematic, because it would imply that once the health of the PLWHA is restored, he/she faces the prospect of losing their grant.

## **2.8. Conclusion**

The literature review has indicated that the socio-economic impact of HIV/AIDS has a detrimental effect on households directly affected by HIV/AIDS. Studies suggest that poorer households are the most severely affected if the breadwinner becomes ill or dies of HIV/AIDS-related illnesses. Studies conducted in South Africa, other African countries and developed countries reported that poorer households are more affected when a household member has HIV/AIDS. Disability Grants in South Africa play a major role in households with little or no income, and provide a safety net to households affected by HIV/AIDS.

There is limited information in the published literature regarding the perceptions of Disability Grants of people with HIV/AIDS within a local Western Cape community with a high

prevalence of HIV/AIDS. The present study provides information which will contribute to this body of knowledge.

University of Cape Town

## **Chapter 3**

### **Research methodology**

#### **3.1. Introduction**

This chapter describes the methodology used in conducting this study: the research design, sampling, setting and rapport with participants, ethical considerations and data collection. The data analysis is also presented. I opted to use the first-person voice in this study, which is an acceptable practice in qualitative studies (Webb 1992).

##### **3.1.1. Research design**

A qualitative, exploratory and contextual research design was utilised to explore HIV-positive people's perceptions and experiences of the usefulness of Disability Grants in their lives. This exploratory design evolved as a result of interest by the researcher, as described in Chapter one. Polit and Hungler (2006:197) stated that "exploratory studies are undertaken when a new area or topic is being investigated, and qualitative methods are especially useful for exploring a little-understood phenomenon". This qualitative exploratory and contextual design allowed the researcher to look for patterns which emerged from the data. Qualitative methods allow participants' voices to be heard.

#### **3.2. Study population and sampling**

This research study focused on three groups of adults in the community attending the clinic who were HIV positive, had been on HAART for more than 6 months, and were receiving a Disability Grant; adults who had been on HAART for more than 6 months whose grants had been terminated because their CD4 counts were more than 200 cells/mm; and adults on HAART who had not received a Disability Grant because their CD4 counts were more than 200 cells/mm.

##### **3.2.1. Sample**

In focus group research, potential participants should have a common experience that is key to the research focus (Asbury 1995). Purposive sampling in qualitative research allows for the

inclusion of research participants who are best able to provide the information under investigation. Barruso and Sandelowski (2003) note that designs in qualitative research are typically emergent, and that therefore sampling intentions when entering the field of study may legitimately not coincide with sampling outcomes leaving the field of study.

Potential participants were approached (see section 3.2.2, Gaining access) and then grouped according to preselected inclusion and exclusion criteria relevant to the research question. Participants were recruited on the basis that they came from the same background, attended the same clinic and had common experiences related to the research topic.

Participants were selected on the basis of the following inclusion and exclusion criteria:

Criteria for selection:

- Adults on HAART for more than 6 months who were receiving Disability Grants (group one).
- Adults on HAART for more than 6 months whose grants had been terminated because their CD4 counts were  $>200$  cells/mm<sup>3</sup> (group two).
- Adults on HAART for more than 6 months who had never received a Disability Grant because their CD4 counts were  $>200$  cells/mm<sup>3</sup> (group three).

Exclusion criteria:

All HIV-positive persons on HAART who were sick, for example, those who had TB, Kaposi's sarcoma, HIV psychosis or a grade 4 peripheral neuropathy. This was assessed on the basis of the patient's history, physical symptoms and clinical examination.

### **3.2.2. Gaining Access to the study population**

Access to the City of Cape Town clinic was gained through consultation with the Clinic Manager. A letter for permission to conduct the study was drafted and sent to the Area Manager of the Southern Suburb District (Appendix E). Access to the DTHF was gained via consultation with the researcher's Line Manager. A letter of permission to conduct the study was drafted and sent to the Director of DTHF (Appendix C).

Once the relevant permissions had been obtained, I explained the process of the study to the counsellors at the clinic. Access to the study population was gained via the counsellors from DTHF as well as the counsellors, nurses and pharmacist of the City of Cape Town, who screened clinic attendees for eligibility and verbally asked potential participants if they would

like to participate in the study. Prior to the recruitment the researcher held a meeting with the Clinic Manager and staff to explain the purpose of the study as well as the consent process. All the staff members involved in recruiting were given a copy of the inclusion and exclusion criteria. According to Stewart, Shamdasani and Rook (2007) FGDs should comprise 6-12 participants. Initially more participants were recruited than were needed as there was the possibility that some would not arrive. This proved to be correct.

Potential participants were told that the study would involve a group discussion. Initially it was proposed that a letter would be drafted to invite potential participants to participate in the study and that this letter would be placed at the reception area. After discussion with the clinic staff, it was felt that this would breach potential participants' confidentiality and expose their HIV status. The counsellors, pharmacist and nurses therefore explained the study in detail to potential participants during consultations, asked them for their home address and contact number, obtained permission for me to contact them, and informed them that they would contact them once approval for the study had been obtained from all the relevant authorities.

Potential participants were given a brief explanation of the consent process. Those who agreed to be contacted were then grouped according to the criteria for selection. All potential participants were contacted telephonically and given the date, time and venue for the FGDs. I explained to potential participants that the FGD would take 1½ - 2 hours, that written consent would be taken, participation was voluntary and that refreshments would be served after the FGD. I asked them for their contact details and permission to contact them, and when a suitable time would be for them to participate. Potential participants were contacted one week prior to the dates of the FGD and reminded the day before.

### **3.3. Collection of data**

#### **3.3.1. Data collection method**

The methodology selected for this research was that of the FGD, making use of a facilitator who was fluent in the local language (see 3.3.4). For the purpose of this study I chose to conduct three different categories of FGDs. The first FGD consisted of 'adults on HAART for more than 6 months who are receiving a Disability Grant', the second 'adults on HAART for more than 6 months whose Disability Grant has been terminated because their CD4 count

was more than 200 cells/mm<sup>3</sup>, and the third group of ‘adults on HAART for more than 6 months who have not received a Disability Grant because their CD4 count was more than 200 cells/mm<sup>3</sup>. The reason for choosing three different focus groups was to explore and interpret their perceptions and understanding of the role and function of a Disability Grant and its perceived benefit for them being HIV/AIDS positive and using HAART, and whether their perception of a Disability Grant may affect decision-making with respect to adherence to ARV therapy.

In qualitative research when using FGDs the group should comprise members of the larger population who have experienced the phenomenon under study (Stewart et al. 2007).

Therefore, focus group participants were “selected according to the basis of their common experience related to the research topic” (Holloway & Wheeler 1996:146).

For this study the participant sample recruited was appropriate to the research topic and had similar roles and experiences according to the stated inclusion criteria.

The FGDs were conducted with adults who had agreed and were willing to be interviewed. FGDs are “characterised by the use of interaction between the participants, from which the researcher discover how individuals think and feel about particular issues” (Holloway & Wheeler 1996:145). Specific questions were tailored each FGD; in the case of ‘adults on HAART for > 6 months who are receiving a Disability Grant’, for example, “What challenges will you face if/when your grant is terminated?”

### **3.3.2. Rationale for FGDs**

FGDs were chosen as opposed to individual interviews. Potential participants can be assembled within a reasonable period (Stewart et al. 2007), and FGDs allow for interactive discussion, generation of new questions and ideas. FGDs enable “participants to explore and stimulate ideas based on shared perceptions of their situation in their own words” (Holloway & Wheeler 1996: 145).

This was an appropriate method for the aim of the study, as it provided the space in which the researcher could explore participants’ needs, feelings and perceptions of a Disability Grant in the context of being HIV/AIDS positive and on HAART. FGDs allowed participants not only to respond to the facilitator, but to other group members as well, and this can be seen as an advantage of an FGD.

### **3.3.3. Formulating the questions**

The five general questions for each group dealt with the grant, how it facilitates adherence and the participants' knowledge about grants (Appendix B). The specific questions were relevant to each of the three individual focus groups.

The design of questions was developed in consultation with clinic staff and my own experience. The set of questions for the FGDs was pretested by a group of counsellors in the workplace, checking to see if they were easily understood. With their input questions were modified so that they could be understood by all of us involved with the FGDs.

### **3.3.4. Role of the facilitator and scribe**

The facilitator or moderator of an FGD plays a crucial role. As the study population comprises primarily first-language Xhosa speakers, it was necessary to have a facilitator who was fluent in English and Xhosa. The focus group facilitator was a staff member of the DTHF. She was a counsellor but not familiar with the study participants. The researcher, facilitator and the scribe all had training and experience in conducting FGDs. Two persons acted as scribes: the first scribe was a DTHF staff member who was also fluent in English and isiXhosa, and I acted as the second scribe. The role of the first scribe was to capture the conversation in both languages. To minimise any bias and in order to observe the group dynamics, I was not part of the discussion group but sat outside the circle of chairs and acted as the second scribe. I was able to ask questions for clarification when participants spoke in Xhosa.

### **3.3.5. Setting and rapport with participants**

The FGDs were conducted in the boardroom of Masiphumelele Clinic on different days, as arranged with each group of participants. The setting was comfortable for participants (Asbury 1995). The facilitator arrived before the commencement of the focus groups to arrange the venue seating and set out refreshments. The facilitator greeted each participant on arrival and welcomed them to the group. The facilitator also played the role of interpreter.

### **3.3.6. Role of the participants in the FGDs**

The participants invited to the FGDs were both willing and able to provide information that was appropriate and applicable to the research study. The list of questions asked at each FGD were open-ended, and in this way allowed and invited participants to talk about their

experiences, raise their opinions and acknowledge their suggestions, thus giving them a feeling of being listened to and that their input was valuable.

Before commencement of each FGD the participants were welcomed to the group and thanked for attending. Thereafter the facilitator, second scribe and I introduced ourselves to the group. The consent process was completed prior to commencement of the discussion.

To maintain confidentiality and anonymity transcribing codes were given to both males and females (e.g. M01 for males and F01 for females, this number increasing depending on the number of males or females present in the group). Every male and female participant was given a label with a coded number by which they could be identified.

This was followed by group member introductions as well as participants telling the group a bit about themselves, their families and some non-intimate personal information. Stewart et al. (2007:95) state that this is a “good way to build rapport and a sense of the group”. Prior to commencement of the FGDs a clearly identified agenda was drawn up. This agenda was not the same as the questions asked. The facilitator also negotiated with the groups the agenda which would govern the process. The facilitator put the group at ease and then started with general questions applicable to the FGDs and continued to the more specific questions. The facilitator conducted the discussion according to a written set of questions. She involved all the participants and did not allow any individual to dominate the discussion. Each participant was given the chance to answer all the questions asked. The FGD lasted approximately 1½ hours. The facilitator also acted as the interpreter to give me a better understanding when the participants could not express themselves in English. The first scribe did a direct translation of the Xhosa language discussion into English.

After completion of the FGD, while the participants were having their refreshments, I played back the recorded interviews to them and gave them an opportunity to see if they were satisfied with their responses. No data were retracted by the participants.

### **3.3.7. Benefits of the focus group method for this study**

The FGDs enabled me to elicit information on a limited number of issues, but enough to permit a genuine discussion among participants in the group. They allowed me to have some

degree of immersion in the participants' lives. For me, FGDs provided useful information and offered the following advantages:

- The FGDs allowed me to interact directly with the participants. This gave me the opportunity to clarify any responses as well as following up any queries arising from the discussions, in this way not having to follow-up later on any FGDs. FGDs also gave me the opportunity to observe the non-verbal responses, which at times supplemented the information supplied or contradicted participants' verbal response. All the questions were asked in English, and all the participants responded in English for my benefit. When they had difficulty answering in English, they answered in isiXhosa, and this was immediately translated into English for my understanding by the facilitator. I then recorded in written form the facilitator's translation. All field notes were written in English by the first scribe for my benefit.
- The FGDs provided an open-response format, and this provided me with an opportunity to obtain valuable amounts of data in the participants' own words.

### **3.4.Ethical considerations**

The study adhered to the principles of the Declaration of Helsinki (Seoul version, 2008). Voluntary informed written consent was obtained from all participants before commencing the FGDs. The consent form was provided in English, since the participants had requested this. Some of the participants asked for verbal translation of the consent form into IsiXhosa, but preferred to read and sign the consent form in English. Verbal translation of English to isiXhosa was done by the facilitator, who is fluent in both languages. All participants were able to read and write, and therefore no independent witnesses were needed for the informed consent process.

A copy of the consent form was given to each participant by the facilitator. Before signing, all the participants were questioned for comprehension of the consent form, as well as being given the opportunity to ask questions to confirm their understanding of the study and commitment involved in participation. This process of informed consent was set firmly within the principle of respect for autonomy, because the participants were informed that their participation was voluntary and that they could withdraw at any stage. The consent form

provided details of the purpose of the study, potential risks and the right to withdraw consent at any time. Confidentiality, anonymity, and possible benefit from the research as well as the use of transcribing equipment were explained. Codes instead of names were utilised for anonymity and participant confidentiality (Appendix A).

Approval for the study was sought from the Human Research Ethics Committee of the Faculty for Health Sciences at the University at Cape Town. A letter of permission was submitted to the researcher's workplace (DTHF) as well as the City of Cape Town (Masiphumelele Primary Health Care Clinic) to gain access to the study population (Appendices D and E).

All data were stored on my personal computer, which is password-controlled, and no access was given to the data other than to the interpreter and the supervisor.

It is appreciated that a study such as this could have been emotive, and when some participants experienced distress, arrangements were made for the person to be referred to a counsellor, which they declined, verbalising that the FGD helped them to express themselves.

There were no direct benefits or risk for the participants. No reimbursements were given, but refreshments were provided.

### **3.5 Data analysis**

#### **3.5.1. Transcription of data**

To familiarise myself with the FGDs I personally transcribed each recorded discussion. All FGDs were transcribed within 24-48 hours after the focus groups. Each FGD and field notes were fully transcribed by me, the pages numbered and marked with the date and number of participants present on the day. While transcribing the data I was able to formulate my initial impressions and make notes to inform data analysis. Observations were recorded in the transcript as well as descriptive accounts as a result of my watching and listening. The notes taken by the scribe and me during the FGDs were added and compared. Non-verbal cues such as facial expressions and gestures by the participants were also included in the transcription by me.

### **3.5.2. Preparation of data for analysis**

Each FGD was coded. Three copies of the transcripts were made, one of which was a clean copy without comments. The interviews were all typed up according to the different FGDs. The headings for each FGD were: Focus Group Text; Own Words; Code and Code Explanation (Appendix J).

### **3.5.3. Methods and stages of analysis**

The method and stages of data analysis utilised was that of thematic analysis, where themes are visible “through manifestation and expression of data” (Ryan & Bernard 2003:85). With the recorded focus group interviews, provisional themes were initially identified during transcription. Thematic analysis focused on identifiable themes and patterns of experiences. All related data were classified into patterns. Thereafter related patterns were grouped into sub-themes emerging from the recorded FGDs. In this way a comprehensive view of information is obtained. Thereafter a valid argument was built for choosing the themes. This was done by reading related literature and thereafter formulating theme statements to develop a storyline (Ryan & Bernard 2003:89).

### **3.5.4. Data analysis process**

I familiarised myself with the data by re-reading and re-listening to the data several times, and in this way looked for indicators of categories of events and behaviour, which were named and coded. It was important to bracket out my own interpretations of the data as much as possible in order to allow the participants’ voices to be heard. As a HIV specialist nurse who has been working in the area for a number of years, this was particularly important. All three groups’ responses to each general question were analysed together, and specific questions were analysed group by group. In this way it was possible to analyse the participant responses in order to identify consistencies and differences (Taylor-Powell & Renner 2003). To bring meaning to the words I identified themes or patterns and organised them into coherent categories. I used the colour-coding strategy to represent each theme that emerged, which helped to organise the data into categories (Appendix J). Themes that arose from each FGD were examined and compared to each other. This was done until all themes and categories were identified and labelled.

### **3.6 Scientific rigour of the study**

#### **3.6.1. Trustworthiness**

To represent reality or truth in any qualitative study, trustworthiness must exist according to Guba and Lincoln (1985, cited by Holloway & Wheeler 1996:162). The central concept of the research process must be demonstrated by the researcher through a ‘decision trail’ that can be followed by other researchers. By maintaining this ‘decision trail’, the researcher must be able to clarify and justify both the chosen methodology and data analysis (Holloway & Wheeler 1996). Trustworthiness and the ‘decision trail’ are the two elements that ensure rigour in qualitative research. Maintaining trustworthiness in qualitative research is through the tenets of credibility, transferability, dependability and confirmability, and in this way qualitative researchers attain quality and can effectively evaluate their research.

##### **3.6.1.1. Credibility**

In qualitative research credibility must be established by the researcher to ensure that those participating in the study are identified and described accurately. According to Koch (1994, cited by Holloway & Wheeler 1996:164) “credibility is enhanced when the researchers describe and interpret their experience as researchers, thus showing their own involvement.” Early familiarity and prolonged involvement is considered to promote the credibility of qualitative research (Shenton 2004). I have worked in the community of Masiphumelele for 6 years, for the first 4 years working as a clinical nurse practitioner in an ARV clinic, and thus had enough time to learn about the culture and build trust with the participants in the FGDs. I understood the participants and had spent time in the research setting. Working with the participants over a period of four years gave me an opportunity to observe the concerns of the participants that were studied, allowing enough time for selecting what was relevant and representative for the issue of Disability Grants and their role in HAART in this community. My experience of working with the participants in Masiphumelele contributed to interpretation of the findings. Credibility was established through clear identification of the participants and the research process by appropriate sampling and use of carefully specified inclusion and exclusion criteria.

Peer debriefing to improve credibility was done throughout the study, and my supervisor and I met on a regular basis during the research process to ensure rigour in this study (Shenton 2004).

Member checks to improve credibility were done through playing back of each audio-recorded FGD to the group while they were having refreshments. This was done so that participants could check that the information was true to their experience. Participants were given the opportunity to request that information they were not satisfied with be removed. No participant wanted any information omitted. The facilitator, scribe and I checked the field notes to ascertain that the correct information had been captured.

### ***3.6.1.2. Transferability***

This limited study comprised a small sample size and is not generalisable, which is the norm for small qualitative studies. However, the study could be transferable to similar populations in peri-urban communities in the greater Cape Town area.

### ***3.6.1.3. Dependability***

This study was able to be audited by the supervisor and the University of Cape Town Research Ethics Committee. An audit trail of field notes and verbatim transcriptions of the interviews was kept. Quotes from the transcriptions are used in support of the data analysis.

### ***3.6.1.4. Confirmability***

Confirmability is established when the reader is able to assess the adequacy of the research process and ascertain if the findings came directly from the data, and whether the data are linked to their sources to establish that interpretations and conclusions arose directly from them (Holloway & Wheeler 1996). Having worked in this community for a long time and understanding the challenges faced by the participants helped me to interpret the data.

## **3.5. Conclusion**

This chapter provided the outline of the study design and the research process. The data collection and process of analysis have also been described. Audio-recorded interviews were transcribed verbatim and typed up, using the field notes as a guideline. The transcribed interviews were read line by line and similarities were colour-coded. The major themes emerged from these categories. Each FGD transcript was analysed separately. The findings of the FGDs are presented in Chapter 4.

## **Chapter 4**

### **Presentation of Findings**

This chapter describes the research findings from the three FGDs conducted. Themes which emerged from the data analysis are presented with respect to the objectives of the study, namely:

- To determine perceptions of the purpose and function of Disability Grants among persons who are HIV positive in the Masiphumelele community.
- To explore with participants whether their perception of Disability Grants may affect decision-making with respect to adherence to ARV therapy.

Two major themes emerged from the data analysis:

- Disability Grants as a means of survival
  - ❖ Unemployment and grants
  - ❖ The benefit of Disability Grants
- Disability Grants and their role in HAART.

#### **4.1. Description of the participants**

All 15 focus group participants were African IsiXhosa-speaking, with English as their second language, which was spoken with varying degrees of competence. The participants comprised males and females between the ages of 24-55 years. Their levels of education ranged from no formal schooling to post-secondary education. One participant had no formal schooling, 13 had secondary education and one had a tertiary qualification. Two of the 15 participants had completed a course in HIV/AIDS counselling. Employment opportunities in the area are limited, and this was evident in the participants' employment status. Of the 15 participants in the FGDs, three were employed in the informal sector, four employed in the formal sector and eight were unemployed.

**Table 4.1 Demographic characteristics of focus group participants**

Age (yrs)	Gender	Marital status	Education	How long HIV+ (yrs)	Employment status	Length of time on ARVs (yrs)	FGD
33	Female	Single	Grade 12. Short course in office administration	9	Employed	7	FGD3
31	Male	Single	Grade 12. Short course in drama	9	Employed	7	FGD3
30	Female	Single	Grade 11. Course in HIV/AIDS	10	Employed	7	FGD3
39	Male	Single	Grade 8. No further education	8	Unemployed	7	FGD3
24	Female	Single	Grade 12. Studying Business Management at Cape Town College	3	Unemployed	3	FGD3
27	Female	Single, in relationship	Grade 12. No further education	3	Employed	2	FGD2
47	Female	Single	Grade 10. No further education	6	Unemployed	6	FGD2
31	Female	Single	Grade 12. No further education	6	Employed	6	FGD2
42	Female	Single	Grade 9. No further education	4	Unemployed	4	FGD2
40	Female	Single	Grade 10. No further education	10	Unemployed	5	FGD2
55	Female	Single	Grade 8. No further education	3	Unemployed	3	FGD2
32	Female	Single	Grade 12. No further education	5	Employed	5	FGD2
46	Female	Single	Grade 9. Course in HIV/AIDS counselling	9	Employed	5	FGD1
26	Female	Single	Grade 11. No further education	2	Unemployed	2	FGD1
55	Male	Married	No formal schooling	3	Unemployed	3	FGD1

Most participants in the FGDs were female. In FGD1, seven participants were invited but only two females and one male attended. Similarly, in FGD2 seven females attended, even though 10 participants were invited (there were no male attendees in FGD2). In FGD3, three females and two males attended. All participants reported taking HAART, with treatment duration ranging from six to 60 months.

## 4.2. Research findings

The research findings are presented in the two themes and two subthemes which emerged from the data analysis. I used the respondents' voices, in the form of verbatim quotations, to substantiate my findings through emerging categories (see Appendix H).

### 4.2.1. Disability Grants as a means of survival

The role and benefit of a Disability Grant is that these grants are playing an important part in the lives of the Masiphumelele community, and are sometimes their only means of survival.

#### 4.2.1.1. Unemployment and grants

For all the participants in the FGDs, whether employed or unemployed, social/Disability Grants played a major role in their survival and well-being. As the majority of the participants were unemployed, social/Disability Grants played a major role in alleviating poverty and were their only means of income. They were unable to consider any other option apart from the support offered through the Disability Grant, as evidenced by these participants:

*“The grant must be given to people who are sick and not working”* (FGD1, M01)

*“If you suffer and don't work, you can apply for a grant”* (FGD1, F01)

Women, particularly those with children and who were unemployed, were considered to be very vulnerable, and the grant was important to their welfare:

*“Social grants is helpful to those who are not working, more especially to mothers who are not working and those who don't have partners. Who are not married and who are not working”* (FGD2, F03)

Participants also perceived grants as money to be awarded to them when unmarried so that they could have dependable financial support:

*“Most people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get a grant, not only sick people”* (FGD1, F02)

All the participants wanted to be employed, but at the time of the study only seven of them were employed. The participants felt that due to their unemployment status, they should be

grant recipients. They perceived the grant to be given to people who are unemployed, not only to those who are ill. Unemployment was seen to be the criterion upon which a grant should be provided by the State. For them this grant was seen as a right:

*“We do have the right to get the social grant because we are sick. I am thinking about people who are HIV positive because we are sick. We need some money to buy food....”* (FGD3, F01)

Participants felt that the government has a responsibility to provide social assistance and that they were entitled to receive Disability Grants because they are unemployed and because they are HIV positive. Their reasoning was that they are unable to find employment and there is a high unemployment rate in South Africa. Participants believe that because they have no income, they are entitled to access assistance from government:

*“A social grant is for when you can’t afford something. If you are not working, government will give you money to support and feed yourself. This is called a social grant”* (FGD 3, M02)

Participants were disappointed in the governmental response to their plight, as they are unable to access a disability/social grant, despite their vulnerable status:

*“The government has let us down. They promised us houses and work but nothing had happened”* (FGD1, M01)

The participants perceived the Disability Grant as being something that one received when one was unable to afford basic necessities such as food and clothing. There was a general awareness and agreement that the grant was not meant for luxury items but should assist persons to meet their basic needs. Their main concern centred around nutrition so they could feed their children, spouses, themselves and sometimes their extended families. As a result of unemployment, they had no other means of income; there was an expectation that the government would provide monetary support so that they could afford basic necessities.

In each group participants considered unemployment and poverty to be their main problems, which led to their suffering. Participants felt that grants relieved unemployment:

*“I think that those who are on ARVs and are not working should qualify. People with chronic diseases should also get it because they are getting it; it is not only for those who are HIV positive. My mom has got asthma and she is getting a grant for that. You*

*can ask a doctor for it and say that you are not working, because you are taking this for the rest of your life and also because you are not working therefore you can apply for a grant” (FGD2, F03)*

Participants recognised that HIV was a chronic illness and that this meant that ARVs would need to be taken for life. Participants in all three FGDs were aware of the criteria for the awarding of a Disability Grant. They felt strongly that being HIV positive on treatment as well as being unemployed should make them eligible for a Disability Grant. The grant was perceived to play major role in alleviating poverty. They perceived that other people with chronic illnesses seemed to be eligible for a grant, and felt that the same rights should be afforded to those who were HIV positive and unemployed.

#### **4.2.1.2. The benefit of Disability Grants**

In Masiphumelele at the time of the study the HIV/AIDS prevalence was 26%. At the end of January 2011, 839 people were in care and were accessing ARVs. More than half of the FGD participants were unemployed. Most of the households were also by women, who were either widowed, divorced or common-law wives.

Those participants who were employed were working in the informal sector. The majority of the participants in the FGDs were the breadwinners, but their inability to find employment led to financial hardship. The benefit of a Disability Grant therefore played a vital role in supporting participants and their families. The benefits of the Disability Grant were expressed by all the participants in all the FGDs. Their understandings of benefits are outlined below.

##### **(a). Grants provide for children**

The majority of the focus group participants were female. The women’s concerns were mainly about the well-being of their children and that their children will be well cared for when they are no longer there to care for them. Feeding, clothing and educating their children were seen as a top priority, thus making the Disability Grant very beneficial in meeting these needs. The grant was also very useful when they had no financial support from the fathers of their children:

*“Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant not only sick people” (FGD1, F02)*

Participants, especially those who had no support from the fathers of their children and the fathers whose wives have passed away, said the grant should be given to them and not only to those people who have chronic illnesses. All participants who were unemployed received Child Care Dependency grants and had a daily battle to provide nutrition for their children and themselves:

*“I don’t think the social grant is only for those who are HIV positive. It is also for those who are not working, who can’t work for her or himself. If you feel fit and healthy you can go and work, but for those who can’t work they need a grant. You can have a grant for 6 months for those not working and for those who have children to support”* (FGD3, F03)

During the wet and cold Cape winter months and especially in the harsh living conditions in Masiphumelele, participants said that receiving a Disability Grant would enable them to buy warm clothing, especially for their children and themselves. They stated that access to the Disability Grant would enable them to provide the necessary winter protection for their children:

*“Buy the clothes to keep warm, not fancy clothes, but to keep warm, insurance and burial policy for my child. Preparation for funeral. Money for my child to go to school. My child is HIV negative”* (FGD3, F03)

**(b). Grants provide for people without partners**

Participants said that grants should not only be given to people who are sick, but should also be awarded to single parents if they had no other means of income, as this will help them to overcome hardships:

*“Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant not only sick people”* (FGD1, F02)

Single parents would then be able to support their children, by feeding, clothing and educating them:

*“All social grants is helpful to those who are not working, more especially to mothers who are not working and to those who don’t have partners. Who are not married and they are not working”* (FGD2, F03)

**(c). Grants relieve suffering**

All the participants understood suffering as being unemployed, not having an income, being unable to support their children and families and not having enough food to eat. Suffering was synonymous with hardship and struggling to survive in all aspects of life. Therefore if they have access to a Disability Grant, the grant would alleviate their suffering:

*“If you suffer and don’t work you can apply for a grant” (FGD1, M01)*

This was echoed by another participant:

*“Social grant is for those people not working, for those who are suffering. For those who are sick with HIV or TB. It is not for everybody who is not working, but for those who are sick” (FGD2, F01)*

**(d). Grants support food security**

As most of the participants were unemployed, there was a constant shortage of food in the household. They also stated that there was limited access to food parcels in the community and that it saddened them that their children had to go hungry. Four of the 15 participants had made the choice to stop taking their ARVs, so that they could access a Disability Grant in order to provide for their children. Participants were aware and had been exposed to health education about the importance of healthy foods. Their main concern was how they could access this healthy food without an income, and felt that having access to a Disability Grant would enable them to purchase healthy food:

*“It is important to get a grant so that your children have food to eat. You can also pay for your children’s school fund” (FGD1, F01)*

Participants lived with the daily reality of hunger, knew that ARVs should preferably not be taken on an empty stomach, but were aware of the danger of stopping their treatment. For the four participants who had made this choice, however, they felt that there was no other option; they had stopped when their CD4 counts went above 200cells/mm<sup>3</sup> so they would be able to access a Disability Grant again:

*“I stopped the ARVs when the grant stopped. I had no money to buy food, so I decided to stop the ARVs. But now I am on ARVs again because I got sick” (FGD2, F01)*

*“The grant is important to buy food to be healthy so that I can take my tablets. It is a must to have food because ARVs give you an appetite. Not fancy food, but healthy food” (FGD3, F03)*

**(e). Grants enable emotional support**

Participants were elated when they received a Disability Grant because it enabled them to do things that they would be unable to do if they had no income:

*“I was very happy. I brought my mom from Graaff Reinet because she was sick. It was a good feeling”* (FGD2, F02)

For others it was a lifeline which came at the point when they thought that they did not have the strength to carry on. This participant, crying and very emotional, stated:

*“By the time it was 2003. I was sick. I was staying with my stepmother and children. I was not working. It was difficult for me. My children had nothing to eat, I had TB, so I decided to go to the clinic ... so the doctor gave me the grant, because at that time I was very frightened my children need food and a place stay”* (FGD1, F01)

Those who had not received this grant appeared to be angry, and were struggling to make ends meet. This was demonstrated through changes in facial expression and tone of voice, and use of hand movements as they talked. One participant displayed anger and was crying because he could not access a Disability Grant. He had tried accessing a Disability Grant on several occasions, but because he was physically healthy and his CD4 count was  $>200$  cells/mm<sup>3</sup>, he had never been successful. He was struggling provide for his family and often was unable to provide food for his children:

*“I asked the doctors but they told me that I was healthy and must go and work. I felt so sad because the owner wanted the rent and I also need to buy food for my children and when I came for my visit I couldn't get the money”* (FGD3, M01)

**(f). Grants provide financial security**

Disability Grants provide financial security in many ways. Some participants said that they were more independent and did not have to rely on their parents or family for financial aid:

*“I think that the grant helped a lot, as a young girl I am no longer depending on my mother. I know that on the third of each month I will get my money. I am now independent and I don't have to depend on anybody”* (FGD1, F02)

Participants who had relatives in other areas of South Africa, particularly in this community, who have their roots in the Eastern Cape, were very aware of the expectations of financial support from their families in the rural districts of the Eastern Cape. Disability Grants were used not only to support themselves but also to help family members:

*“It helped to buy clothing. My mother is in Eastern Cape and I could send her money. When you in Cape Town your relatives expect you are working and you must send them money to the Eastern Cape” (FGD2, F07)*

Disability Grants also played a major role for those participants whose family members were not supportive and could not support them financially:

*“Social grant is very helpful because sometimes your family is not supportive so you can buy food and the burial society” (FGD3, F02)*

**(g). Grants increase/provide an extra income**

Participants who were employed said that they were earning insufficient money to support themselves and their families, and felt that a grant increased their income. This would also relieve their stress:

*“If you are not earning enough, things you can’t buy, using transport, not enough money to buy groceries. Even if you are working you can apply for a grant if you don’t have enough money. You can get the grant even if you are working, as long as you earn a little money so the social grant can add to what we earn” (FGD3, M02)*

They saw the grant as supportive, but would rather have had employment which would have enabled them to support themselves and their families:

*“I never wished to depend on a grant. I wanted a stable job. I need a good job because the one that I have is paying next to nothing. If I had a grant I would be better off. If they give you a grant and they take it away it is stressful. They can give me something small, a small grant to start a business” (FGD2, F05)*

In all three FGDs participants did not believe that stopping their ARVS was the right thing to do because they wanted to work. The reality for them was that formal employment was scarce, many had insufficient skills and informal work did not provide sufficient income.

Thoughts of the well-being of their children took preference in most of their decisions:

*“My grant was stopped, but I never thought to stop ARVs. I thought about my children. What would happen to my children if something happened to me? (FGD2, F05)*

Participants said that if you earned a limited income, a Disability Grant could augment the monthly income:

*“Social grant is for someone who is not working and not earning enough money so that it can help you. If you are working and earning less than R1000.00 per month government is giving you some money called a social grant” (FGD3, F01)*

**(h). Grants create security**

Participants perceived grants as money to be awarded to them if they are unmarried so that they have a financial means which they can depend on. Even though some of them are employed and earning a low salary, a grant can be awarded to them so that they have more money at the end of the month:

*“Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant, not only sick people” (FGD1, F02)*

The Disability Grant is perceived by some as helping them with some method of payment for their children:

*“I don’t think the social grant is only for those who are HIV positive. It is also for those who are not working, who can’t work for her or himself. If you feel fit and healthy you can go and work, but those who can’t work they need a grant. You can have grant for 6 months for those not working and have children to support” (FGD2, F03)*

For some of the participants the Disability Grant was perceived as something that one should be entitled to if not earning enough:

*“If you are not earning enough, things you can’t buy, using transport, not enough money to buy groceries. Even if you are working you can apply for a grant if you don’t have enough money. You can get the grant even if you are working, as long as you earn a little money so the social grant can add to what we earn” (FGD3, M02)*

**(i). Grants provide for funeral cover, investment and education**

For all the participants having funeral cover played a major role in their lives, due to the high cost of a funeral. They wanted to shift the burden away from their children or family members and wanted to pay for their funerals themselves:

*“To buy some food and some clothes. To make the funeral cover. Especially for the funeral cover” (FGD2, F03)*

Receiving a Disability Grant made it possible for them to pay for a funeral and other policies.

[Laughing] *“I was very excited; I thought I was going to buy everything for myself. The grant made me feel better. I could pay funeral service and buy my things. I felt better because I knew I had money coming in” (FGD2, F05)*

They also wanted their children to benefit financially should they pass away. They were keen to ensure that their children could further their education, and wanted investment policies:

*“The grant provide for insurance and burial policy for my child. Money for my child to go to school. My child is negative” (FGD3, F03)*

*“Firstly, if the grant is terminated it will make me suffer. My life would come to a standstill. My policies will be stopped. How can I look after the children without the money?” (FGD1, F01)*

The importance of adequate provision for their families was a strong feeling among the participants that was captured by this one:

*“Buy the clothes to keep warm, not fancy clothes, but to keep warm. Insurance and burial policy for my child. Preparation for funeral. Money for my child to go to school. My child is HIV negative. Food to be healthy so that I can take my tablets. It is a must to have food because ARVs give you an appetite. Not fancy food, but healthy food” (FGD3, F03)*

#### **4.2.2. Disability Grants and their role in HAART**

Disability Grants were considered a vital component of the lives of persons who are HIV positive in Masiphumelele. In FGD 2, four participants had stopped taking their grants so that their CD4 counts could drop below 200 cells/mm<sup>3</sup>, in order to access a Disability Grant. They had decided to stop treatment as they were hungry and desperate, and had no other choice since they were unable to find employment. Those who were employed worked on a casual basis in the informal sector, with no security and few future prospects.

##### **(a). Grants enable adherence**

The grant enabled the participants to buy food and take their medications as prescribed and support adherence:

*“I think it helps a lot 'cause when you are on ARVs the doctor always say that you must eat healthy food. When you get the grant you can usually buy what the doctor says so that you can eat healthy...” (FGD1, F02)*

*“Disability Grant is very important to those who are taking ARVs, because ARVs need to be taken with food, the other ARVs can be taken without food. It is difficult to take ARVs without food. If you are not working and your partner is not working, you having this Disability Grant, then if you are not having this Disability Grant you feel you don't want to take your ARVs” (FGD2, F03)*

In all the FGDs participants knew of the risk of stopping their ARV medication – that they would become very ill and would have to recommence the medications, and that this put their lives at risk:

*“I think it is bad. I stopped the ARVs when the grant stopped; I had no money to buy the food, so I decided to stop the ARVs. But now I am on ARVs again because I got sick, so very sick, so I said OK I must go back and take my ARVs again. I stopped taking my ARVs for 3 years, start getting sick last month and started to take my ARVs now in May 2010 again” (FGD2, F01)*

*“I stopped taking ARVs so that my CD4 can go down so that I can get the grant, the money. I stop taking ARVs. I was followed up. I never wanted to come back. But when I got sick I came back for ARVs” [A lot of laughter, but later she cried] (FGD2, F04)*

The four participants who had stopped taking their ARVs had relapsed, and three had been hospitalised:

*“I think that it is not good, for most of the people doing that, the others have died when they stopped their ARVs, because they want the grant. They are dying because they stopped taking the treatment because they want the grant to be continued. You see this is bad. The terrible thing about this, they are playing with their lives. When my grant stopped, I just think about my children and I think about me, because I want to see this children growing up. I'm not getting this grant and it is very dangerous to stop the treatment. If you stopped on this first line then there is the other option, the second line, and when you stop the second line there is no other option and then you are going to die. I don't want to die. But when they want this grant they want to stop the ARVs (FGD2, F03)*

*“I think it is not right to stop the ARVs because money is not more important than your life. I also stopped my treatment. I went to doctor, I told her I was not working. My child is also HIV positive, I begged my doctor for my child also, I didn’t get the grant, so I come to the clinic again when I get sick when my child was more sick. I am now back on treatment” (FGD2, F02)*

Non-adherence to ARVs was not seen as a solution for other participants, as they were concerned about the consequences for their children should they relapse if they stopped their ARVs:

*“I never thought of stopping ARVs when the grant stop. I don’t see stopping ARVs as a solution” (FGD2, F07)*

Finding employment was viewed a better option than stopping ARVs:

*“My grant was stopped, but I never thought to stop ARVs. I thought about my children. What would happen to my children if something happened to me? I never wished to depend on a grant. I wanted a stable job. I need a good job because the one I have is paying next to nothing. If I had a grant I would be better off. If they give you a grant and they take it away it is stressful.” (FGD2, F05)*

#### **(b). Grants enable good health**

All the participants said that the grant facilitated good physical and mental health, because not only could it provide for food and other basic necessities, but emotionally they felt less stressed:

*“There was a change in my health because I was stressed. I stopped the ARVs to drop my CD4 count, but they never gave me a grant again. I only came back last month to take my ARVs again. But I need a grant but don’t know how to get it. I still need a grant because I am not well. They still say that I am alright. I started in 2005 and stopped in 2009. I restarted in May 2010. It doesn’t help to stop ARVs if you don’t get a grant” (FGD2, F04)*

*“Social grant is important because we are not working and as HIV-positive people we need to eat healthy vegetables and food” (FGD3, M01)*

Participants said that if they had access to a Disability Grant they could afford to buy healthy food such as vegetables for themselves and their children:

*“Getting a grant helped me to stay healthy and I am also now able to pay for the education of my children” (FGD1, M01).*

They said that food will make them healthy because some ARVs must be taken with food:

*“Food to be healthy so that I can take my tablets. It is a must to have food because ARVs give you an appetite. Not fancy food but healthy food” (FGD3, F03)*

### **4.3. Conclusion**

The themes which emerged from the FGDs clearly demonstrate the importance of the Disability Grant in all aspects of the participants' lives. Numerous benefits of the grant were highlighted by participants. The grant was perceived as something without which it was impossible to manage. For most of the grant receivers, it was the only source of income and their lifeline to survival. Participants felt that, if unemployed, they should be entitled to receive the grant. The well-being of children took preference over everything, to the point of considering non-adherence to their ARV regimen in order to access a Disability Grant. All of the participants valued food security as a benefit of receiving a Disability Grant, because good nutrition added quality to their lives.

## **Chapter 5**

### **Discussion of findings**

#### **5.1. Introduction**

This chapter presents a discussion of the research findings.

#### **5.2. Disability Grants as a means of survival**

It is clear from the findings of the study that Disability Grants are seen as essential to daily survival and recipients in order to provide basic necessities for their families. Unemployment was a major issue for the FGD participants.

##### **5.2.1. Unemployment and grants**

The South African unemployment rate remains high (4.1 million persons in 2010) (Statistics SA 2010). The community of Masiphumelele comprises mainly black Africans, who have the highest unemployment rate at 23%.

Masiphumelele is a predominantly young community, with 56% of the population between the ages of 20-39 years (+- 9509 people; Masiphumelele Census 2010). The unemployment rate for the youth is high, and this is consistent with the national average unemployment rate (Quarterly Labour Force Survey, 2010). A study conducted by Kingdon and Knight (2007:835) reported that “unemployment is worse for the young because older workers’ jobs are protected by firm-specific human capital or legislation resulting in new entrants to the labour market bearing the brunt of the labour market competition.”

Fuelled by the high unemployment rate, high HIV/AIDS prevalence (26%) and high levels of poverty in Masiphumelele, Disability Grants not only play a major role in alleviating poverty, but for the study participants were the major – and for some the only – source of income. The participants in the FGDs had very limited access to formal employment. A South African Government commission found that “where a grant exists there is improvement in household health, access to education and job seeking opportunities” (Goldblatt 2009:369).

With the advent of the ARV roll-out programme in 2004, many of the participants' health had improved and they considered themselves well enough to be employed. They reported that they wished to find employment, but that this had been difficult. This study's finding is consistent with research conducted by Manuela de Paoli, Backer-Gronningsaeter and Mills (2010) in peri-urban areas of Cape Town similar in demographic profile to Masiphumelele, Khayelitsha, Nyanga, New Crossroads, Somerset West and Hout Bay. They found that healthy and able-bodied PLWHA were seeking employment, but that the employment sector was saturated, particularly for those seeking unskilled labour.

Participants' HIV status was also an additional barrier to getting into the labour market. Participants verbalised that unemployment and poverty as well stigma also impacted on their ability to find work – therefore the importance of the grant. This finding is consistent with the study by Manuela de Paoli et al. (2010), who also reported that unemployment and poverty were the main problems identified by respondents.

There was a strong belief by the study participants that the government has a responsibility to provide them with social assistance and that they are entitled to receive Disability Grants because they are HIV positive. Noble, Ntshongwana and Surender (2008:10-11) in South Africa reported that respondents viewed the government as being responsible for those who are unemployed, except when people had been retrenched. Respondents said it was the government's primary responsibility to support those who became sick and those with no recent employment. The social grant system currently does not extend to those who are unemployed. Noble et al. (2008) found that support for a grant was strongest among the poor, and that the unemployed person felt that there should be some form of grant support.

The high rates of unemployment and poverty are entrenched in the historical and political context of South Africa. In 1996 a new Constitution and Bill of Rights was enacted. Through this there was an expectation of restoration of justice and provision of an adequate social security system for the poverty-stricken and unemployed. Through a high-profile political commitment, the government shifted to a "social model" with respect to the allocation of grants to address previous injustices during apartheid. In this context a social model of disability can be seen as "a socially created problem, rather than an individual one" (Goldblatt 2009:370). The government argued that this new system of "comprehensive social

security not be based solely on an assessment of the health condition by a doctor, but on a 'needs based assessment', by a panel including lay people". However this system was largely criticised for its subjectivity by many social anthropologists (MacGregor 2006:3). Noble et al. (2008) also reported that they had found that respondents wanted improved spending on social grants. Another finding noted that those who were employed supported an increase in taxes to enable more welfare spending.

Each province has a different approach to the assessment of disability (Simchowitz, 2004, cited by Manuela de Paoli et al. 2010). Some rely on evaluation by medical officers or district surgeons, and others on an assessment panel. The Western Cape uses medical officers to assess the level of disability. The Western Cape has followed the *Guidelines for Medical Assessment of Disability for Social Assistance Purposes* since 2010 (Appendix I), because of the problems created when awarding grants to HIV/AIDS with a CD4 count of 200 cells/mm<sup>3</sup> and below. As this study was conducted prior to these guidelines being issued, the guidelines that were applicable during the study period were based on Disability Grants being awarded to persons with clinical stage 3 and stage 4 HIV/AIDS as well as a CD4 count of 200 cells/mm<sup>3</sup> and less.

### **5.2.2. The benefits of Disability Grants**

South Africa has a large non-contributory social security system. Disability Grants for the FGD participants played a major role in their lives as well as those of their extended family members. Participants who had received a Disability Grant in the past and who are currently receiving a Disability Grant expressed how beneficial the grant was, not only to them but to their extended families. The participants who had never received a Disability Grant expressed how they would have benefitted had they been able to access the grant. The participants expressed a good understanding of the benefits of a Disability Grant. In this study most of the FGD participants were female and heading a household; this was through being widowed, deserted by their partners, or by choice.

The participants' primary concern was that they needed to care for their children, and in particular that the children were fed, educated and clothed. Thereafter, the benefits of Disability Grants were that they provided for people without partners, relieved suffering and enabled emotional support. This finding is consistent with those of a study conducted by

Phaswana-Mafuya et al. (2009) in the Eastern Cape, where they found that the Disability Grant was used to buy basic necessities including food to take treatment, transport to treatment sites, and to take care of their family needs such as school fees, health, clothes and food. Being able to afford food, funeral policies and clothes were high priority for the participants of the study conducted by Phaswana-Mafuya et al. (2009), which also indicated that it also helped them to care for other ill household members in this way improving the health of the entire household. Other studies have reported similar findings (MacGregor 2006; Gilbert & Walker 2009; Manuela de Paoli et al. 2010).

For all participants of the FGDs, adequate food/nutrition was important. They spoke of a continual shortage of food in their households, especially those who were unemployed and not receiving a grant. This placed the family at increased risk for health-related problems. Participants reported that even though they were referred to a social worker for a food parcel, they seldom received assistance. Difficulty in taking ARVs on an empty stomach as a result of not having enough food can affect adherence to ART. Nutrition plays an important role in PLWHA as it contributes to improved immune status. A study conducted in Niger by Serrano et al. (2010) found that a Family Nutritional Support programme given when initiating ART was beneficial for survival of PLWHA. The mortality rate was reduced and the CD4 count was 1.7 times greater after 6 months on this nutritional support programme. This study showed evidence of reducing the risk of progression of primary AIDS and death.

Cantrell et al. (2008) in a study in Zambia found that adherence to ART was higher among PLWHA who received nutritional support when initiating ART. Forty eight of the study participants met the criteria for food insecurity, and this could pose a significant threat to the long-term success of ART programmes in resource-poor settings. Cantrell et al. (2008) argue that in order to achieve sustainable long-term ART outcomes, nutritional support is an essential component of integrated HIV care and treatment.

The benefits of the Disability Grant are demonstrated in a study by Manuela de Paoli et al. (2010), who found that they were used towards general household expenses and were often the main source of income in a household. As the Disability Grant was utilised for the household as well as the individual's expenses, there was pressure on the participants who were receiving a Disability Grant.

In the current study participants who received the Disability Grant were pleased to do so, but those who had not met the criteria for the grant were angry and stressed. The difference that the grant made for the participants was to enable them to provide for their children and themselves. This reduced the constant stress of trying to make ends meet. Phaswana-Mafuya et al. (2009) also reported that buying food and caring for their children was a top priority for the participants in their study.

### **5.3. Disability Grants and their role in HAART**

For the study participants the Disability Grant was, for most of the time, the only source of income and acted as a lifeline. Some of them were willing to sacrifice their health so that they could keep the Disability Grant. The desperation to keep the grant can be seen in the four participants who had become non-adherent to the ARV medication regimen so that they could let their CD4 counts drop below 200 cells/mm<sup>3</sup>, in order to access a Disability Grant. This was a survival strategy. This trade-off between health and Disability Grants was documented by Natrass (2004) and Hardy and Richter (2006). Both studies reported that persons on ARVs would stop taking them long enough once their health had improved to allow their CD4 counts to drop below 200 cells/mm<sup>3</sup>, so that the Disability Grant could be reinstated. They would then go back onto treatment. With the high unemployment rate in Masiphumelele, limited skills and few job opportunities in this area, their only survival strategy was to retain the Disability Grant at all costs.

The Disability Grant, primarily seen by government as a temporary form of social assistance to assist the individual and his/her family to have a minimal income during a period of illness, has become the primary means of income for many indigent persons with a chronic illness, of which HIV is but one. The Disability Grant has become such a valuable commodity in terms of generating income for PLWHA that they will do everything in their power to access or remain on the grant. Because there is no other means of gaining an income, the Disability Grant is their only means of survival. The Disability Grant is no longer perceived as social assistance, but as legitimate income.

This pattern of non-adherence to medication has also been seen in TB studies. A study conducted by MacGregor (2006) in Khayelitsha in Cape Town found that participants

expected tangible support from the State, such as a monetary grant to buy food, because as one participant told her, “the grant is what I eat” (MacGregor 2006:11).

Participants were unaware of the risks associated with interruption of the ARV regimen and the challenges and side-effects of second-line therapy. As Natrass (2004) and Simchowitz (2004) stated in their findings, participants not only undermine their own health but will also contribute to the growth of resistant strains of the virus, thereby undermining the effectiveness and raising the cost of the ART.

The participants in FGDs in Masiphumelele were aware of the risks of stopping treatment. Although this option had been considered by some of the FGD participants, for most it was not viewed as a solution. They were concerned of the effects of this decision on their children and their own health. Gilbert and Walker (2009) reported in their study that children were a strong motivating factor to adhere to the medication regimen. Manuela de Paoli et al. (2010) reported in their study conducted in peri-urban areas in Cape Town that there were rumours that some people had stopped taking their ARVs in order to qualify for a grant to alleviate their financial problems, but that stopping ARVs to qualify for a grant was not a common strategy as adherence remained consistently high. Similarly, Masiphumelele FGD participants had a high ARV adherence rate of 94-100%.

Participants in the FGDs said that the grant enabled good physical and mental health because it provided for food and other basic necessities and reduced stress. Phaswana-Mafuya et al. (2009:545) reported that the Disability Grant had a positive impact on treatment adherence and attitude towards treatment, because PLWHA found it easier to take treatment when they were able to buy food, and that without food adherence to ARVs became very difficult. Similarly, a study conducted by Manuela de Paoli et al. (2010:12) in peri-urban Cape Town found that once the health of PLWHA is restored after HAART initiation, this leads to a higher CD4 count and subsequent cessation of the grant. The Disability Grant acted as the only source of income in these households, and the loss of it impacted on emotional and physical health and led to high levels of stress. The loss of a Disability Grant also had direct implications for the health of these participants because they could no longer follow a healthy diet.

The social security system has been a highly contested issue in South Africa, and has come under criticism from many sociologists, anthropologists and medical officers (Phaswana-Mafuya, et al. 2009). The high unemployment rate together with high rates of TB and HIV have led to a significant increase in the number of Disability Grants awarded. With the absence of an effective social security system for the labour unproductive citizens of South Africa, the Disability Grant offers financial security not only for the survival of the individual, but for the extended family as well.

The method of using the CD4 count to determine a person's eligibility for a Disability Grant to date has proven to a large extent to be unreliable. Some PLWHA can have a CD4 count  $< 200$  cells/mm<sup>3</sup> and not be limited in their activities of daily living and still capable of continuing their normal jobs (Phaswana-Mafuya et al. 2009). Due to this inconsistency of awarding grants across the provinces, all medical officers must now follow the new *Guidelines for the Medical Assessment of Disability for Social Assistance Purposes*, because there is no official policy document on disability-related medical assessments for PLWHA. Therefore this document serves as a method to breach this gap in policy (Appendix I).

#### **5.4. Limitations of the study**

This limited size qualitative study has reported findings in one local community. Qualitative studies are not generalisable, but the findings of this study may be transferable to similar settings.

A significant challenge in this study was the difficulty in ensuring that persons who had agreed to participate did in fact attend the FGDs. All participants were notified timeously, but despite reminders the attendance at each group varied, and this could have influenced the overall findings. Possible reasons for this include other conflicting appointments, fear of being stigmatised and health-related issues. There may also have been reluctance to openly discuss a sensitive issue such as Disability Grants, if the potential participant in any way felt that his/her chances of retaining or accessing the grant would be jeopardised by participation in the study.

Language usage in this study could have influenced the freedom that participants felt to speak about the questions. The researcher attempted to ensure that this limitation was minimised through the use of a Xhosa-speaking facilitator and scribe, and direct translation as necessary.

## **5.5. Recommendations**

A number of recommendations can be made based on the findings of this study.

### **Recommendations for Government**

The perception of the value of the Disability Grant as not only being for those who qualify through eligibility of illness/disability criteria, but a regular income support, needs to be considered by the relevant governmental structures.

The BIG (Basic Income Grant), a grant of R100.00 per month, which would be awarded to all citizens and recovered through taxation from those with sufficient income, has been proposed as one solution to the alleviation of poverty in South Africa. To date, however, this has not been approved. It is clear though that a suitable programme for upliftment of the poor and those with chronic conditions is an urgent need.

There is an urgent need for a strategy that supports PLWHA who are well enough to work but are unable to find employment, either due to their own lack of suitable skills or the competition for scarce employment in the current economic downturn. This study has highlighted the willingness of PLHWAs to contribute to their own income generation. Innovative strategies involving all relevant stakeholders are required to support PLWHA and ensure that they are able to support themselves for as long as possible, and that there is an appropriate support structure for the periods during which they need social assistance.

The gaps in the current system of social assistance need to be reduced to ensure that those who are maintaining good health on chronic medication such as ARVs do not become non-adherent in order to access social assistance.

Clear guidelines for assessment of a person's eligibility for social assistance should be available, regularly reviewed and adhered to. One of the current challenges is that the main responsibility for such assessment lies with the medical officers; it should rather be done in

conjunction with a social worker report, so that a more holistic approach can be taken to social assistance.

### **Recommendations for communities**

The need for appropriate skills development is evident. For young people in particular, suitable training for employment in the labour force is an urgent need. Although this is a recognised need for all unemployed, it is particularly important for persons with a chronic illness such as HIV, to reduce the dependency that people feel – in part because of the chronic condition, but also due to their frustration at not being able to provide for themselves and their families.

### **5.6. Conclusion**

This study aimed to explore HIV-positive persons' perceptions of the usefulness of Disability Grants and their contribution to health and well-being while on HAART. A secondary objective was to explore whether the perception of the value of the Disability Grant may influence the decision of PLWHA to adhere to an ARV treatment regimen or not.

It is evident from the findings that the Disability Grant is considered an essential source of income, and for some is the sole means of survival. The participants in this study felt that the awarding of social assistance should go beyond the Disability Grant, but be extended to those who are unemployed as well as those living in poverty. This study's findings concur with those of previous studies in highlighting the importance of social assistance in the form of a Disability Grant for PLWHA. However, the Disability Grant cannot be seen as the answer to the financial welfare of such persons. In the current economic climate there are enormous challenges faced by government to provide for the poorest and most needy of its citizens. The Disability Grant is one mechanism to meet the needs of those with HIV who are unable to work – but there is a large gap which needs to be addressed.

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## Appendix A

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT: The Role and Function of a Disability Grant and perceived benefit for persons on HAART in Masiphumelele Community**

**PRINCIPAL INVESTIGATOR: Helen Woolgar**  
**ADDRESS: 5 Bishopstone Road, Wetton Park, Ottery, 7800**

**CONTACT NUMBER: (h) 021-7036598, cell: 0725881077**

You are being invited to take part in a research project. The project is part of the requirements for MSc Nursing by course work and dissertation at the University of Cape Town. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any question about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are **also** free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Research Ethics Committee, Faculty of Health Sciences, the University of Cape Town** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (Seoul version 2008) South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. The proposal has been approved by the UCT Faculty of Health Sciences, Research Ethics Committee“(REC REF)”.

#### **What is this research study all about?**

- The project will determine your perceptions of the purpose and functions of a disability grant and also if disability grants may affect your decision-making with respect to adherence to HAART.
- You will be in a group of eight to ten people attending Masiphumelele clinic. As the researcher, I will ask you questions about your perceptions of the role that a disability grant plays in a person’s life. Interpreters will be present if you struggle to understand or answer the questions in English. Your answers will also be tape recorded. The study will

be conducted in the boardroom of the Desmond Tutu HIV Foundation clinic at the Masiphumelele Primary Health Care Clinic. The focus groups will last approximately 1½ hours and will be held during the day at a time to suit everyone.

**Why have you been invited to participate?**

- You have been invited to participate because the investigator wants to explore the role and function of a disability grant and the perceived benefit for persons on HAART in the Masiphumelele community.

**What will your responsibilities be?**

- To answer all questions as honestly as possible.

**Will you benefit from taking part in this research?**

- There are no personal benefits at present.

**Are there risks involved in your taking part in this research?**

- There are no risks involved, as confidentiality will be maintained at all times. I will ask you to respect each other's information during the focus group discussion. Should you be receiving a disability grant at the time of the focus group, this information will not be linked to your name. Your name and any personal details will be confidential you will not be able to be identified in the report. Should you feel in any way upset as a result of taking part in the focus group, counselling will be available to you at no cost to you.

**Who will have access to your information?**

- The investigator, the thesis supervisor and the Department of Health and Rehabilitation Sciences: Division of Nursing and Midwifery will have access to the information. The information collected will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study but refreshments will be provided for each study visit. There will be no costs involved for you, if you do take part.

**Is there any thing else that you should know or do?**

- You can contact Dr. Pat Mayers (Thesis supervisor) at tel: 021-4066464 if you have any further queries or encounter any problems.
- You can contact the Research Ethics Committee at 021-4066492 if you have any concerns or complaints that have not been adequately addressed.
- You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled (*The Role and Function of a disability grant and the perceived benefit for persons on HAART in the Masiphumelele Community*).

I declare that:

- I have read or had read to me this information and consent form and it is written and verbally translated in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) ..... on (*date*) ..... 2010.

.....  
**Signature of participant**

.....  
**Signature of witness**



## **Appendix B**

### **General Questions for each group**

1. What is your understanding of a social grant and the reasons for obtaining a grant?
2. When should persons who are HIV + be able to apply for a grant?
3. Who do you think should qualify for a grant?
4. What do you think are the benefits of receiving a grant for persons who are HIV+?
5. Some people may think about stopping their ARV medication if they are scared of losing their disability grant. What do you think about that?

### **Adults on HAART for > 6 months who are receiving disability grant (Group A)**

1. At which point in your illness did you apply for a grant?
2. How long did it take to receive the first grant payment?
3. How long have you received a grant?
4. What is your experience of receiving a grant?
5. What challenges will you face if/when your grant is terminated?

### **Adults on HAART for > 6 months whose grants have been terminated because their CD4 count are > 200cell/mm<sup>3</sup> (Group B)**

1. At which point in your illness did you apply for a grant?
2. How long did it take to receive the first grant payment?
3. How long have you received a grant?
4. What was your experience of receiving a grant?
5. Were you given a reason why your grant was stopped
6. Since your grant was terminated, has there been any change in your health and daily living activities?

### **Adults on HAART for 6 months who have not received a disability grant because their CD4 count are >200 cells/mm<sup>3</sup> (Group C)**

1. Have you ever applied for a grant? (for HIV or other reason)?
2. What is your opinion of the reasons for which a grant is provided for HIV+ persons?
3. If you have applied for a grant because you are HIV positive, and were informed that you did not qualify, were you given reasons?
4. Have you been offered or sought any other social assistance?

**Appendix C**

5 Bishopstone Road  
Wetton Park  
Ottery  
7800  
28 February 2010

The Director of Desmond Tutu HIV Foundation  
University of Cape Town  
Medical School  
Anzio Road  
Observatory  
7800

Dear Professor Wood

**Re: Study Entitled “The Role and Function of a disability grant and the perceived benefit for persons on HAART in the Masiphumelele Community”**

I would like to request permission to conduct the above-mentioned study to investigate the role and function of a disability grant and the perceived benefit for persons on HAART in the Masiphumelele Community. The study is in partial fulfilment of the requirements for the M Sc Nursing by course work and dissertation at UCT.

I would like to commence with the study in December 2009 and aim to submit the research report for examination in August 2010. The full proposal is attached. I plan to interview, using a focus group method, adults on HAART for more than 6 months who are receiving disability grants, adults on HAART for more than 6 months whose grants have been terminated because their CD4 counts are  $>200$  cells/mm<sup>3</sup>, adults on HAART for more than 6 months who have never received a disability grant because their CD4 count are  $>200$  cells/mm<sup>3</sup>. The study will be conducted at the Desmond Tutu HIV Foundation at Masiphumelele Clinic.

The study will be conducted under the supervision of Mrs Pat Mayers, Senior Lecturer, Division of Nursing and Midwifery, UCT. “(REC REF)” Ethics approval has been obtained from the Research Ethics committee.

Please contact me should you require any further details to discuss the project more fully. Contact numbers are as follows: (w) 021-7855486 (c) 0725881077.

Yours sincerely

H.L. Woolgar (Mrs)

**Appendix D**

5 Bishopstone road

Wetton Park

Ottery

7800

28 February 2010

The Research and Ethics Committee

Faculty for Health Sciences

University of Cape Town

Cape Town

8000

Dear Sir/ Madam

**Re: Permission to conduct a study entitled “The Role and function of a disability grant and the perceived benefit for persons on HAART in the Masiphumelele Community”**

Please find attached my proposal, for the above study. The proposed study is to be conducted as part of the requirements for the M Sc nursing by course work and dissertation MM017.

Consent will be obtained from all participants, focus group interviews will be conducted privately and confidentiality will be maintained at all times.

I would like to commence the study from April 2010-August 2010. The study will be conducted at the Desmond Tutu HIV Foundation in the Masiphumelele Primary Health Care Clinic.

I am applying for expedited review, as there is minimal risk to participants.

Please contact me should you require any further details. Contact numbers are as follows: (w) 021-7855486 (h) 021-7036596 (c) 0725881077

Yours sincerely

H.L. Woolgar (Mrs)

Student number: PTRHEL002

## Appendix F

### The South African Antiretroviral Treatment Guidelines 2010

Standardised national ART regimens for adults and adolescents

<b>First Line:</b>		
All new patients needing treatment, including pregnant women	TDF + 3TC/FTC + EVF/NVP	For TB co-infection EFV is preferred. For women of child bearing age, not on reliable contraception, NVP is preferred
Currently on d4T based regimen with no side-effects	D4T + 3TC = EFV/NVP	Remain on d4T if well tolerated. Early switch with any toxicity .Substitute TDF if at high risk of toxicity (high BMI, low hb, older female).
Contraindication to TDF: renal disease	AZT +3TC +EFV/NVP	
<b>Second Line:</b>		
Failing on d4T or AZT-based 1 <sup>st</sup> line regimen	TDF +3TC/FTC +LPV/r	
Failing on a TDF-based 1 <sup>st</sup> line regimen	AZT = 3TC = LPV/r	
<b>Salvage:</b>		
Failing any 2 <sup>nd</sup> line regimen	Specialist referral	

## Appendix G

### Code list for Focus Groups

**FGD 1 (A): Adults on HAART for >6 months who are receiving a disability grant**

**FGD 2 (B): Adults on HAART for > 6 months whose grants have been terminated because their CD4 counts are > 200**

**FGD 3 (C): Adults on HAART for 6 months who have not received a disability grant because their CD4 count are >200**

#### **1. Grants relieve unemployment**

**FGD1:** *“The grant must be given to people who are sick and not working.”*

*“If you suffer and don’t work you can apply for a grant.”*

**FGD 2:** *“...all social grants is helpful to those who are not working more especially to the mothers who are not working and those who don’t have partners. Who are not married and they are not working.”*

**FGD 3:** *“A social grant is for when you can’t afford something. If you are not working, government will give you money to support and feed yourself. This is called a social grant.”*

#### **2. Grants provide for children**

**FGD 1:** *“Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant not only sick people.”*

**FGD 2:** *“I don’t think the social grant is only for those who are HIV+. It is also for those who are not working, who can’t work for her or himself. If you feel fit and healthy you can go and work, but those who can’t work they need a grant. You can have a grant for 6 months for those not working and have children to support.”*

**FGD 3:** *“The grant provide for insurance and burial policy for my child. Money for my child to go to school. My child is negative.”*

#### **3. Grants provide for people without partners**

**FGD 1:** *““Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant not only sick people.”*

**FGD 2:** *““...all social grants is helpful to those who are not working more especially to the mothers who are not working and those who don’t have partners. Who are not married and they are not working.”*

#### **4. Grants enable adherence**

**FGD 1:** *“I think it helps a lot cause when you are on ARV’s the doctor always say that you must eat healthy food. When you get the grant, you can usually buy what the doctor says so that you can eat healthy...”*

**FGD 2:** *“Disability grant is very important to those who are taking ARV’s, because ARV’s Disability grant is very important to those who are taking ARV’s, because ARV’s need to be taken with food, the other ARV’s you can take without food. It is difficult to take ARV’s without food. If you are not working and your partner is not working, you having this disability grant, then if you not having this disability grant you feel like you don’t want to take your ARV’s.”*

**FGD 3:** *“As someone who is taking ARV’s it is important to eat because ARV’s are being taken at times.”*

#### **5. Grants relieve suffering**

**FGD 1:** *“If you suffer and don’t work you can apply for a grant.”*

**FGD 2:** *“Social grant is for those people not working, for those who are suffering. For those who are sick with HIV or TB. For those who are sick and HIV+. It is not for everybody who is not working but for those who are sick.”*

#### **6. Grants enable food security**

**FGD1:** *“I think it helps a lot cause when you are on ARV’s the doctor always say that you must eat healthy food. When you get the grant, you can usually buy what the doctor says so that you can eat healthy...”*

**FGD2:** *“When you are sick and not working, you can’t take the medication on an empty stomach you should get the grant to buy food.”*

**FGD 3:** *“We do have the right to get the social grant because we are sick. I am thinking about people who are HIV positive, because we are sick. We need some money to buy food. People who have asthma and other diseases can also apply for grant, not only those who are HIV positive.”*

## **7. Grants increases/provides an extra income**

**FGD 1:** *“We will never survive without a grant more especially if you are sick and have no job.”*

**FGD 2:** *“My grant was stopped, but I never thought to stop ARV’s. I thought about my children. What would happen to my children if something happened to me? I never wished to depend on a grant. I wanted a stable job. I need a good job because the one I have is paying next to nothing. If I had a grant I would be better off. If they give you a grant and they take it away it is stressful. They can give me something small, a small grant to start a business.”*

**FGD 3:** *“Social grant is for someone who is not working and not earning enough money so that it can help you. If you are working and earning less than R1000.00 per month, government is giving you some money called a social grant.”*

## **8. Grants create security**

**FGD 1:** *“Most of the people get the grant when they have young children or are single mothers and single fathers. The grant must be given to them. They must get the grant, not only sick people.”*

**FGD 2:** *“I don’t think the social grant is only for those who are HIV+. It is also for those who are not working, who can’t work for her or himself. If you feel fit and healthy you can go and work, but those who can’t work they need a grant. You can have grant for 6 months for those not working and have children to support.”*

**FGD 3:** *“If you are not earning enough, things you can’t buy, using transport, not enough money to buy groceries. Even if you are working you can apply for a grant if you don’t have enough money. You can get the grant even if you are working, as long as you earn a little money so the social grant can add to what we earn.”*

## **9. Grants enable good health**

**FGD 1:** *“Getting a grant helped me to stay healthy and I am also now able to pay for the education of my children.”*

**FGD 2:** *“There was a change in my health because I was stressed. I stopped the ARV’s to drop my CD4 count, but they never gave me a grant again. I only came back last month to take my ARV’s again. But I need a grant but don’t know how to get it. I still need a grant because I am not well. They still say that I am alright. I started in 2005 and stopped in 2009. I restarted in May 2010. It doesn’t help to stop ARV’s if you don’t get a grant.”*

**FGD 3:** *“Social grant is important because we are not working and as HIV positive people we need to eat healthy vegetables and food.”*

### **10. Grants enable emotional support**

**FGD 1:** *“Crying and very emotional. “By the time it was 2003, I was sick. I was staying with my stepmother and children. I was not working. It was difficult for me. My children had nothing to eat, I had TB, so I decided to go to the clinic .....so the doctor gave me the grant, because at that time I was very frightened my children needed food and a place to stay.”*

**FGD 2:** *“I was very happy. I brought my Mom from Graaf Reinet because she was sick. It was a good feeling*

**FGD 3:** *“I asked the doctors but they told me that I was healthy I must go and work. I felt so sad because the owner wanted the rent and I also needed to buy food for my children and when I came for my visit I couldn’t get the money.”*

### **11. Grants provide financial security**

**FGD 1:** *“I think that the grant helped a lot, as a young girl I am no longer depending on my mother. I know that on the third of each month I will get my money. I am now independent and I don’t have to depend on anybody.”*

**FGD 2:** *“It helped to buy clothing. My mother is in Eastern Cape and I could send her money. When you in Cape Town your relatives expect you are working and you must send them money to the Eastern Cape.”*

**FGD 3:** *“Social grant is very helpful because sometimes your family is not supportive so you can buy food and the burial society.”*

### **12. Grants provide for funeral cover, investment and education**

**FGD 1:** *“Firstly if the grant is terminated it will make me suffer. My life would come to a standstill. My policies will be stopped. How can I look after the children without money?”*

**FGD2:** *(laughing) “I was very excited, I thought I was going to buy everything myself. The grant made me feel better. I could pay funeral service and buy my things. I felt better because I knew I had money coming in.”*

**FGD3:** *“Buy the clothes to keep warm, not fancy clothes, but to keep warm. Insurance and burial policy for my child. Preparation for funeral. Money for my child to go to school. My child is HIV-. Food to be healthy so that I can take my tablets. It is a must to have food because ARV’s give you an appetite. Not fancy food, but healthy food”*

### **General Questions**

**1. What is your understanding of a social grant and the reasons for obtaining a grant?**

- Grants relieve unemployment
- Grants enable medication
- Grants provide food security
- Grants provide an extra income
- Grants are for illness
- Grant provide for children
- Grants for low CD4 count
- Grants for the disabled
- Grants relieve suffering
- Grants provide for those without partners
- Grants increases your income
- “Dependency issues”

**2. When should persons who are HIV+ be able to apply for a grant?**

All 3 focus groups answered when your CD 4 count is low or when your CD4 count is, 200cells/mm<sup>3</sup>

**3. Who do you think should qualify for a grant?**

- Those on TB treatment and who is HIV+
- Those who are on HAART/ARVs

- Those who are ill and unemployed
- Those on ARVs who cannot afford to buy food-grant enables medication
- People who have other chronic illnesses
- People who are unemployed
- People who are struggling
- Those who are ill and cannot afford to buy food
- Those who are single, are sick and cannot afford to support their children
- Those people who are HIV+ and whose CD4 counts are  $<200\text{cells}/\text{mm}^3$

4. **What do you think are the benefits of receiving a grant for persons who are HIV+?**

- Grants provide for clothing
- Grants provide for insurance policies
- Grants provide for burial policy for myself and for my children
- The grant enables medication
- The grant enables adherence
- The grant provide for food security
- The grant pays for school fees
- Grants provide for my children
- The grant pays for school fees
- The grant provide for my children's future
- Grants help to buy a school uniform
- Grants help to further my studies/tertiary education



University of Cape Town

## Appendix H

**Table of emerging categories**

<b>Emerging Category</b>	<b>Respondent's voices</b>
Grants relieve unemployment	<i>“Social grant is helpful to those who are not working, more especially to the mothers who are not working and for those who do not have partners.”</i>
Grants provide for children	<i>“It is important to get a grant so that your children have food to eat. You can also pay your children's school fund.”</i>
Grants provide for people without partners	<i>“Most people get the grant when they have young children or are single mothers and single fathers. The grant must be give to them. They must get the grant, not only sick people.”</i>
Grants enable adherence	<i>“I think it helps a lot cause when you are on ARVs the doctor always says that you must eat healthy food. When you get the grant you can usually buy what the doctor says so that you can eat healthy.”</i>
Grants relieve suffering	<i>“If you suffer and don't work you can apply for a grant.”</i>
Grants enable food security	<i>“Disability grant is very important to those whoa are taking ARVs, because ARVs need to be taken with food. It is difficult to take ARVs without food.”</i>
Grants increases/provides an extra income	<i>“Social grant is for someone who is not working and not earning enough money so that it can help you. If you are working and earning less than R1000.00 per month</i>

	<i>government is giving you something called a grant.”</i>
Grants enable dependency issues	<i>“Even if you are working you can apply for a grant if you don’t have enough money. You can get a grant even if you are working, as long as you earn a little money.”</i>
Grants enable good health	<i>“Getting a grant helped me to stay healthy and I am also now able to pay for the education of my children.”</i>
Grants enable emotional support	<i>“I was very happy. I brought my Mom from Graaf-Reinet because she was sick. It was a good feeling.”</i>
Grants provide financial security	<i>“I think that the grant helped a lot, as a young girl I am no longer depending on my mother. I know that on the third of each month I will get my money. I am now independent and I don’t have to depend on anybody.”</i>
Grants provide for funeral cover	<i>“To buy some food and clothes. To make the funeral cover. Especially for the funeral cover.”</i>

## **Appendix I**

### **Guidelines for the Medical Assessment of Disability for Social Assistance Purposes**

The specific guidelines of HIV/AIDS when awarding disability grants are as follows:

- When first diagnosed and current symptoms
- General physical condition
- Record BMI or degree of weight loss over a period of time
- Any recurrent/opportunistic infections. Please describe specific details of each
- CD4 counts and viral loads are not essential. These results should be provided, however if available
- Stage the disease according to WHO staging, motivating clinically your reasons for staging. Remember early HIV is asymptomatic and patients can still work. WHO stages 3 and 4 will be considered for a disability grant. With the availability of antiretroviral therapy, beneficiaries must be aware that compliance with treatment is vital and that any evidence of defaulting treatment or non-compliance disqualify grant eligibility. Please note: There is no special HIV grant.

## Appendix J

**Focus Group B – (Adults on HAART for > than 6 months whose grants have been terminated because their CD4 counts are > 200 cells/mm<sup>3</sup>)** 7 females arrived for this group. There were no male participants. Conducted on 01 June 2010

Focus Group Text	Own Words	Code	Code Explanation
<p><b>General Questions:</b></p> <p><b>What is your understanding of a social grant and the reasons for obtaining a grant?</b></p>	<p><b>F03:</b> “Social grant, all the grants is helpful to those who are <b>not working</b>, more especially to the mothers who are <b>not working</b> and to <b>those who don't have partners</b>. Who are not married and they are not working. Disability grant is very important to <b>those who are taking ARV's</b>, because <b>ARV's need to be taken with food, the other ARV's you can take without food. It is difficult to take ARV's without food.</b> If you are not working and your partner is not working, you having this disability grant, then <b>if you not having this disability grant you feel like you don't want to take your ARV's.</b></p> <p><b>What is your general knowledge of a</b></p>	<p>Grants relieve unemployment</p> <p>Dependency issues Without partners</p> <p>Enables medication/adherence.</p> <p>Food security</p> <p>No grant = no ARVs</p>	<p>The participants felt that due to them being unemployed grants should be allocated to them to relieve unemployment.</p> <p>They perceive grants as money to be awarded to them when they are unmarried so that they have financial means which they can depend on.</p> <p>Even if you are working and earning a low salary a grant can be issued to you so that you have more money at the end of the month.</p> <p>The grant is perceived as helping them for some method of payment for their children.</p> <p>The grant enable participants to buy food and in this way they can take their ARVs on a full stomach.</p> <p>If they do not receive a grant, their mood is a bit low and therefore They have no motivation to take their food.</p>

	<p><b>social grant? (asked by moderator)</b></p> <p>“I don’t think the social grant is only for those who are HIV+. It is also for those who are not working, who can’t work for her or himself. If you feel fit and healthy you can go and work, but those who can’t work they need a grant. You can have grant for 6 months for those not working and have children to support.”</p> <p><b>F01:</b>” Social grant is for those people not working, for those who are suffering. For those who are sick with HIV or TB. For those who are sick and HIV+. It is not for everybody who is not working but for those who are sick.”</p> <p><b>F02:</b> “I think the social grant is for those who are on ARV treatment and for those who are not working.”</p>	<p>Grants relieve unemployment</p> <p>Grants for illnesses.</p> <p>Grants relieve suffering</p> <p>Grants provide for my children</p> <p>Grants relieve suffering</p> <p>Grants for illnesses.</p> <p>People on treatment need grants. Grants relieve unemployment.</p>	<p>Being unemployed is a reason for receiving a grant</p> <p>For those who can’t work in this way the grant will relieve suffering.</p> <p>Grants are granted to those with other illnesses.</p> <p>For those with children and unemployed the grant can provide for them.</p>
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	<p><b>F05:</b> “The grant I know is the grant for TB, HIV and for the child.”</p> <p><b>F04:</b> “I know the grant when you are crippled and deaf.”</p> <p><b>F06:</b> “I know the grant when you have arthritis and you can’t work anymore and you receive a grant.”</p> <p><b>F07:</b> “I know the grant when children lost their parents because of HIV. The children receive grant or the new parent for the children get the grant.”</p>	<p>Grant is also for children.</p> <p>Grant is for other illnesses.</p> <p>Grants for other disabilities.</p> <p>Grants for orphans.</p>	
<p><b>When should persons who are HIV + be able to apply for a grant?</b></p>	<p><b>F02:</b> “I think that when a person who is HIV+ to get the grant is when her CD4 count is down. That is when her CD4 count is under 100.If it is less than 199 or less than 200 because we start the ARV’s when the CD4 count is now less</p>	<p>Access to receiving a grant.</p> <p>Understanding of when you are able to access a</p>	

	<p>than 250 then you can apply for a grant when you are not working and you are not fit.”</p> <p><b>F01:</b> “Even now when your CD4 count is less than 180 you don’t get a grant here in Masi. Even if it is 80 you don’t get a grant. You ask the doctor for a grant, that say that you are fit and that you look alright and that you must go and work, even if your CD4 is 80. Mine was 80 and they said that I must go home and start a job and I must start the ARV’s.”</p> <p><b>F04:</b> “When your CD4 count is low the doctor advise you or give you permission to apply for a grant.”</p> <p><b>F05:</b> “When a person has TB that person qualify for a grant.”</p>	<p>grant.</p> <p>Grant for unemployment.</p> <p>Knowledge of when you can access a grant, but was not given a grant.</p>	
<p><b>Who do you think should qualify for a grant?</b></p>	<p><b>F01:</b> “I think that those on TB treatment, they should qualify for a grant.”</p>	<p>TB and HIV+ persons should receive a grant.</p>	

	<p><b>F03:</b> “I think that those who are on ARV’s and are not working should qualify. People with chronic diseases should also get it because they are getting it; it is not only for those who are HIV+. My Mom has got asthma and she is getting a grant for that. You can ask a doctor for it and say that you are not working, because you are taking this for the rest of your life and also because you are not working therefore you can apply for a grant.”</p> <p><b>F07:</b> “When you are not working and you are struggling and not working your family can’t look after you, even your siblings or cousins can qualify for a grant.”</p> <p><b>F06:</b> “When you are sick and not working, you can’t take the medication on an empty stomach you should get the grant to buy food.” She left the</p>	<p>People who are HIV+ and unemployed should receive a grant.</p> <p>Grant relieve unemployment.</p> <p>Chronic illnesses and grants.</p> <p>Grants for asthma.</p> <p>Grants for unemployment and illnesses.</p> <p>Grants relieve unemployment.</p> <p>Grants for other family members.</p> <p>Food security.</p> <p>Unemployment.</p> <p>Grants = ARVs = food.</p> <p>Grants enable</p>	
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	<p>interview after this as she is pregnant and had a doctor's appointment.</p> <p><b>F05:</b> "When you a single parent, are sick, have children at school you can't afford paying school fees for your children, there is a school fund that need to be paid. A single parent should get a grant."</p>	<p>medication.</p> <p>Without partners.</p> <p>Grant pays for school fees.</p> <p>Dependency issues.</p>	
<p><b>What do you think are the benefits of receiving a grant for persons who are HIV+?</b></p>	<p><b>F03:</b> "I think the benefit is to buy the food. While you are receiving the grant, because sometimes you don't have the money to buy food. Even here, you don't have the land to grow your own veggies. You have to buy your own food and also to buy you warm clothes for winter. We don't buy tablets because we are receiving it for free at the clinic. But the food is very expensive."</p> <p><b>F02:</b> "To buy some food and some</p>	<p>Food security.</p> <p>Grants provide for clothing</p> <p>Grant = food security.</p> <p>Grants provide for</p>	<p>Funerals are expensive, but plays a major role in the lives of</p>

	<p>clothes. To make the funeral cover. Especially for the funeral cover.”</p> <p><b>F03:</b> “ Also for the funeral cover. The funeral cover is for myself and for my children. Because when you are not working and you know that you are HIV positive than what about your children and their future after you have passed away? You didn’t even save because you are not working and with that you can save for your children to go to school because you know you are going to die and you want to plan for the future of your children. And when you get the grant you can save for your children.”</p> <p><b>F05:</b> “It helps you to feed yourself, take yourself to the doctor and look after your children.”</p> <p><b>F04:</b> “When you are HIV+ you don’t know when you are going to die so you</p>	<p>funeral cover.</p> <p>Grants relieve unemployment.</p> <p>Grants provide for funeral cover.</p> <p>Grants provide for children’s future.</p> <p>No grant = no saving for the future. Grants help to plan for the future.</p> <p>Grants helps your children when you have died.</p> <p>Food security.</p> <p>Grants provide for children.</p> <p>Grants help with payment of debts.</p>	<p>participants.</p>
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	<p>have to pay your debts and save some money. This money will help you when you die and for benefits.”</p> <p><b>F07:</b> “It helps very much because I was doing a course and I paid for that course with my grant money.”</p>	<p>Grants help financially when you die.</p> <p>Grants help with furthering your studies.</p>	
<p><b>Some people may think about stopping their ARV medication if they are scared of losing their disability grant. What do you think about that?</b></p>	<p><b>F03:</b> “I think that it is not good, for most of the people doing that, the others have died when they stopped their ARV’s, because they want the grant. They are dying because they stopped taking the treatment because they want the grant to be continued. You see this is bad. The terrible thing about this, they are playing with their lives. When my grant stopped, I just think about my children and I think about me, because I want to see this children growing up. I’m not getting this grant and it is very dangerous to stop the treatment. If you</p>	<p>Dependency issues.</p> <p>Stopping ARVs = death</p> <p>Stopping ARVs not good.</p> <p>Children are more important than stopping ARVs. Stopping ARVs are dangerous.</p> <p>ARVs = 1<sup>st</sup> line than</p>	

	<p>stopped on this first line then there is the other option the second line and when you stop the second line there is no other option and then you are going to die. I don't want to die. But when they want this grant they want to stop the grant.”</p> <p><b>F01:</b> “I think it is bad. I stopped the ARV's when the grant stopped; I had no money to buy the food, so I decided to stop the ARV's. But now I am on ARV's again because I get sick, so very sick, so I said OK I must go back and take my ARV's again. I stopped taking my ARV's for 3 years start getting sick last month and started to take my ARV's now in May 2010 again.”</p> <p><b>F02:</b> “I think it is not right to stop the ARV's because money is not more important than your life. I also stopped my treatment. I went to doctor, I told</p>	<p>2<sup>nd</sup> line then nothing available in South Africa.</p> <p>Dependency issues.</p> <p>Stopping ARVs =death.</p> <p>Grants relieve unemployment.</p> <p>Food security.</p> <p>Stopping ARVs is bad.</p> <p>Grant = food security.</p> <p>Stopping ARVs = ill health.</p> <p>Stopping ARVs not the right thing to do.</p> <p>Money not more important than your</p>	<p>Participants value their life more than money.</p>
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	<p>her I was not working. My child is also HIV+, I begged my doctor for my child also, I didn't get the grant, so I come to the clinic again when I get sick when my child was more sick. I am now back on treatment.”</p> <p><b>F04:</b> “I stopped taking ARV's so that my CD4 can go down so that I can get the grant, the money. I stop taking ARV's. I was followed up. I never wanted to come back. But when I got sick I came back for ARVs.”(A lot of laughter), but later she cried.</p> <p><b>F05:</b> “My grant was stopped, but I never thought to stop ARV's. I thought about my children. What would happen to my children if something happened to me? I never wished to depend on a grant. I wanted a stable job. I need a good job because the one I have is paying next to nothing. If I had a grant I</p>	<p>life.</p> <p>Stopped ARVs because grant stopped, was unemployed.</p> <p>No grant = no ARVs. Stopped taking ARVs = Getting sick again. No ARVs decreases CD4 count.</p> <p>No grant – children more important than stopping ARVs to access a grant.</p> <p>Grant increases</p>	<p>Due to unemployment, grant acted as a lifeline therefore participants had no choice but to forgo their ARVs so that they could access a grant.</p> <p>Participants are fully aware of the implications of not taking ARVs to access a grant, but this was done because they were desperate and unemployed.</p>
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	<p>would be better off. If they give you a grant and they take it away it is stressful. They can give me something small, a small grant to start a business.”</p> <p><b>F04:</b> “Is crying, emotionally she is stressed. The group gave her a hug.</p> <p><b>F07:</b> “I never thought of stopping ARV’s when the grant stop. I don’t see stopping ARV’s as a solution.</p>	<p>income.</p> <p>No grant increases stress levels.</p> <p>Grant = start of a business.</p> <p>Not a solution to stop ARVs when grant stopped.</p>	
<p><b>Specific questions</b></p> <p><b>At which point in your illness did you apply for a grant?</b></p>	<p><b>F07:</b> “I applied for a grant when I had TB and the treatment for TB was not suitable for me. I had a reaction to the TB treatment and was hospitalised. When I was discharged from hospital, I asked for the grant and the doctor said I qualified for the grant and so I got the grant.”</p> <p><b>F05:</b> “I was diagnosed in 2001 and received the grant.” (Sighing).I was</p>	<p>Application of grant when she had TB.</p> <p>TB = grant application</p> <p>HIV+ = grant application.</p>	

	<p>stressed and very sick and my CD4 count was low and the doctor gave me the grant in 2002. When my CD4 count got up they took the grant away. I reapplied for the grant and I couldn't get the grant because I was working. I told the doctor that I was working. From R750.00 the grant came down to R500.00 and in December 2009 it stopped. I never reapplied for the grant because it makes me sick and stressed when it is taken away.”</p> <p><b>F04:</b> Still crying/very emotional. I had TB, they took my blood to check the CD4 count and it was 31 and then I applied for a grant.</p> <p><b>F03:</b> “I applied for a grant when my CD4 count was 180. That was in 2001 and I was staying in Khayalitsha. They said I must apply for a grant, but I was not sick.”</p>	<p>Low CD4 count = grant application.</p> <p>Increase in CD4 count = termination of grant.</p> <p>Employment = no grant.</p> <p>Employment = decrease in grant.</p> <p>Re-application of grant = increased stress levels.</p> <p>Low CD4 count not ill but applied for a grant</p>	<p>An understanding of when and why grant is terminated.</p>
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	<p><b>F02:</b> “I applied for a grant in 2003.I was sick. I started with JIV in 200.My CD4 count was 180.”</p> <p><b>F01:</b> “I applied for a grant in 2001.My CD4 count was 80.I had HIV in 1999.When I applied for a grant I was sick.”</p>	Grant application = ill	
<p><b>How long did it take to receive the first payment?</b></p>	<p><b>F03:</b> “I applied for a grant in 2001 and got it in 2001. I waited for the grant for 5 months.”</p> <p><b>F02:</b> “Applied for a grant in 2003 and got it in 2003.”</p> <p><b>F01:</b> “I waited 3 months for the grant.”</p> <p><b>F07:</b> “I took 3 months before getting a grant.”</p> <p><b>F04:</b> “I took 3 months before receiving a grant.”</p> <p><b>F05:</b> “I took 3 months before receiving a grant.”</p>	<p>Waiting period for a grant ranges from 3-5 months.</p> <p>Minimum waiting period for a grant is 3 months.</p> <p>Maximum Waiting period for a grant is 5 months.</p>	

<p><b>How long have you received a grant?</b></p>	<p><b>F03:</b> “I got it for 1 year. It was great to receive the grant. I had to buy nice clothes.”</p> <p><b>F02:</b> “I had it for 6 months. I was enjoying the money. It helped me and my mother.”</p> <p><b>F01:</b> “I had the grant for one year. I enjoyed it. I also bought myself a fridge.”</p> <p><b>F07:</b> “It took a year and it stopped and I asked the doctor and he said I can’t depend on the grant. I must go and look for a job.”</p> <p><b>F05:</b> “Fromm 2002 I got the grant. In 2008 it went down from R750.00 to R500.00. In 2009 it stopped altogether.”</p> <p><b>F04:</b> “I got it for 8 months at first. And then I reapplied. I did not wait a year. I waited months. I got it for 8 months again and it stopped. I was very sick and asked the doctor and the doctor said</p>	<p>Dependency issues.</p> <p>Received a grant between 6 months to 6 years.</p> <p>Minimum time to receive a grant is 6 months.</p> <p>Maximum period to receive a grant is 6 years.</p> <p>Receiving a grant = enjoyment, material benefits.</p>	
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	<p>I was fine. I then left everything.”</p> <p><b>F07:</b> “I didn’t understand when they said you receive a grant for 12 months. When you apply for a grant, you are given it for 3 months then after that you get it monthly for 9 months which come to a year.”</p>		
<p><b>What is your experience of receiving a grant?</b></p>	<p><b>F05:</b> (laughing) “I was very excited, I thought I was going to buy everything for myself. The grant made me feel better. I could pay funeral service and buy my things. I felt better because I knew I had money coming in.”</p> <p><b>F03:</b> “It was great, I bought clothes, furniture. I even bought for my brothers. I thought it was like a present.”</p> <p><b>F02:</b> “I was very happy. I brought my Mom from Graaf Reinet because she was sick. It was a good feeling.”</p>	<p>Receiving a grant = excitement.</p> <p>Receiving a grant = good health.</p> <p>Receiving a grant = access to buy things, pay for funeral benefit.</p> <p>Receiving a grant = income.</p> <p>Grant provided for other family members.</p> <p>Grant= present.</p>	

	<p><b>F01:</b> “I was happy. I had food in the fridge and could buy clothes. I also started ARV’s and feeling very healthy.”</p> <p><b>F04:</b> (crying) “I was excited. I managed to take my son to initiation school. What makes me feel bad is that I thought I could pay my debts and then the grant stopped.”</p> <p><b>F07:</b> “It helped to buy clothing. My mother is in eastern Cape and I could send her money. When you in Cape Town your relatives expect you are working and you must send them money to the Eastern Cape.”</p>	<p>Grant = happiness.</p> <p>Grant = taking son to initiation school.</p> <p>No grant = bad feelings.</p> <p>Grant = paying debts.</p> <p>Grant = buying clothes.</p>	
<p><b>Were you given a reason why your grant was stopped?</b></p>	<p><b>F03:</b> “No reason, no letter was given. I went to the pay point and there was no money. I was sad because I was 8 months pregnant. I was going to buy clothes for this unborn baby. There was no reason on the slip. I went to another</p>		

	<p>table and they told me to go to the doctor with this slip. The doctor reapplied and I got the grant again. In my pregnancy my CD4 count went lower. In 2005 it stopped again with no reason. I did not apply again. I was stressed. In 2003 I joined a support group. I told myself to look for a job and I joined mothers to mothers. I was still qualifying for a grant.”</p> <p><b>F02:</b> “I received the letter that told me that the grant was going to stop in 4 months time and that I must go to the doctor to renew my grant. I went to the doctor and my CD4 count was 250.I got a grant but not for myself, but I got a child support of R140.00 for my child. I am looking after my sister’s child and this gives me something. My sister helps me”</p> <p><b>F01:</b> “I got the letter that said I must go</p>		
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	<p>to the clinic. My CD4 count was up to 480. The doctor said I am better. I felt upset when the grant stopped. I do not have a job and now my boyfriend is helping me.”</p> <p><b>F04:</b> “I was told that the reason they see I am alright then my grant was taken away. They told me that there was other people who need the grant because they are sick. I don’t need it because I am better.”</p> <p><b>F07:</b> “I was told that after 1 year the grant will be stopped because I will be healed from TB.”</p> <p><b>F05:</b> “I received a letter to say that I must reapply. I never went back. I did not like that the grant was decreased. I thought that if I went back for a grant, many questions would be asked. I could not reapply for a grant because whenever I came for clinic visits I was</p>	<p>Good health = no grant.</p> <p>Reapplication for grant = fear.</p>	
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	told I was alright. I was too scared to apply for a grant again.”		
<b>Since your grant was terminated, has there been any change in your health and daily activities?</b>	<p><b>F03:</b> “I told myself that I must wake up and look for a job because it was stressing me. It has changed me, stressing me. I stood up and came to look for work. There was no change in my health. I wanted to stop ARV’s but I was thinking about my children. What is going to happen to my children. My husband is also getting a grant since 2006.</p> <p><b>F02:</b> “I was sad because I was not working. There was a change in my health. I was retrenched as a packer, but was never sick. It did not affect my health.”</p> <p><b>F01:</b> “My health was affected. There was a change in my health, I was very</p>	<p>Grant termination = no change in health. Termination of grant = thoughts of what is going to happen to m children.</p> <p>No grant = sadness = unemployment = change in health status.</p> <p>No grant = change in health therefor no grant</p>	

	<p>sick. I was sick because I stopped using the ARV's not because the grant stopped.”</p> <p><b>F07:</b> “Nothing changed in my health. I am taking my treatment like I am supposed to. But financially I am crippled.”</p> <p><b>F04:</b> “There was a change in my health because I was stressed. I stopped the ARV's to drop my CD4 count, but they never gave me a grant again. I only came back last month to take my ARV's again. But I need a grant but don't know how to get it. I still need a grant because I am not well. They still say that I am alright. I started in 2005 and stopped in 2009.I restarted in May 2010.It doesn't help to stop ARV's if you don't get a grant.”</p> <p><b>F05:</b> “I feel that there must be somebody to check people's condition</p>	<p>= no ARVs = ill health.</p>	
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	<p>so that they know who must get a grant. It is also not good to depend on a grant but there is no jobs so people need grant. When you sick and have children, children need food and clothing.”</p> <p><b>F04:</b> “We need a grant, sometimes you need a grant, children need feeding because you don’t have anything to give them. I used to work, because I was sick every now and then with HIV, I disclosed to employer I was fired. I thought I was helping when I disclosed my status, but everybody stayed away from me, because I was HIV+. One need a grant when you are crippled by illness, you can’t work”</p> <p><b>F01:</b> “The grant comes in the form of money.”</p> <p>F03: “Comes as money, card money from pay point. There are no food vouchers in Khayalitsha , while waiting</p>		
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	<p>for a grant. No food vouchers in Masiphumelele as well.”</p> <p><b>F03:</b> (crying) “I see my friend getting a grant for 5 years. Was HIV+ but not on ARV’s. When grant stopped she reapplied and got the grant again for 5 years. Her husband is also working. They are not getting a grant to those who need a grant. They need to do research door to door then they can come with a reason why you are not getting a grant. There is also a story of ID’s. I’m the sole breadwinner and have 8 people that I am looking after. I told my sister to apply for a grant for her children.I think that he system is failing us.they said that my sister must wait for her ID.”</p>		
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