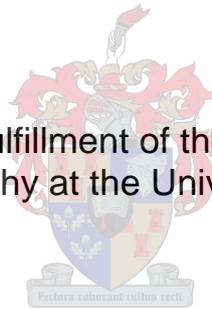


# **INFLUENCE OF DISABILITY GRANTS ON ANTIRETROVIRAL MEDICATION ADHERENCE – A STUDY AT STANGER HIV CLINIC**

**By**

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Thesis presented in partial fulfillment of the requirements for the degree  
Master of Philosophy at the University Stellenbosch



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December 2010

## DECLARATION

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December 2010

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## **ABSTRACT**

Different reports have evidently shown that there are HIV infected individuals on antiretroviral medications who at some points have difficulty with adherence. Various reasons have been proposed for this. However, commonly reported anecdotally is the poor adherence by those benefiting from the government's disability grant as a way of remaining eligible for the grant. The study aimed at exploring various influences that disability grants might have on its beneficiaries (who are HIV positive) in terms of adherence to their antiretroviral medications.

Structured interviews and focus group discussions were the methods of study. Ten adult beneficiaries of the disability grant who are HIV positive and also taking antiretroviral medications were selected from Stanger HIV clinic and requested to voluntarily participate in the structured interviews. Two sets of focus group discussions were conducted for recipients of disability grants who are HIV positive and taking antiretroviral medications too. There were eight participants in each discussion group. In addition to the interviews and focus group discussions conducted as afore mentioned, a medical officer with Stanger HIV clinic and a social worker were selected and individually interviewed. The different participants' responses were compiled and analysed.

The study showed the disability grant is a key motivator to the continual use of ARV medications among the HIV beneficiaries. It serves as the mainstay of life sustenance among them most especially in providing for food and transportation to clinics. Other 'inappropriate' ways of spending the grant were equally identified in the study. The study further found that issue of discontinuing the disability grant by the government was not a welcomed idea among most of the grant beneficiaries.

## OPSOMMING

Verskeie verslae het getoon dat daar persone met MIV en wie op antiretrovirale medikasies is wie sukkel om getrou aan die program te bly. Verskeie redes is hiervoor voorgestel. Nietemin, daar is alledaagse anekdotiese vertellings van die swak vlak van trou bly deur voordeeltrekkers van die regering se ongeskiktheidstoelae as 'n manier om geskik te bly vir die toelaag. Hierdie studie het gepoog om verskeie invloede wat ongeskiktheidstoelaes dalk op voordeeltrekkers uitoefen (wie MIV positief is) te ondersoek in terme van trou bly aan hul antiretrovirale medikasie programme.

Gestruktureerde onderhoude en fokusgroepe is in die studie gebruik. Tien volwasse voordeeltrekkers van ongeskiktheidstoelaes, wie ook MIV positief is, en wie ook antiretrovirale medikasies geneem het, is gelesekteer van die Stanger MIV-kliniek en gevra om vrywillig aan die gestruktureerde onderhoude deel te neem. Twee stelle fokusgroepbesprekings is vir MIV-positiewe voordeeltrekkers van ongeskiktheidstoelae, wie ook antiretrovirale medikasies neem, aangevoer. Daar was agt deelnemers in beide besprekingsgroepe. Bo en behalwe die onderhoude en fokusgroepbesprekings, is individuele onderhoude met 'n mediese beampte aan die Stanger MIV-kliniek en 'n maatskaplike werker aangevoer. Die response van die verskeie deelnemers is toe saamgestel en ontleed.

Die studie het getoon dat die ongeskiktheidstoelae 'n sleutel motiveerder vir die volgehoue gebruik van ARV medikasie onder die MIV voordeeltrekkers is. Dit dien as die steunpilaar vir lewensmiddele onder hulle veral in die voorsiening van voedsel en vervoer na klinieke. Ander 'onpaslike' maniere van spandering van die toelaag is ook in die studie identifiseer. Die studie her verder getoon dat die kwessie van die beëindiging van die ongeskiktheidstoelae deur die regering nie 'n welkome idee onder die toelaag-voordeeltrekkers is nie.

## TABLE OF CONTENTS

Chapter 1: Introduction	6
1.1 Problem Statement	6
1.2 Method of Research	7
1.3 Structure of the Study	7
Chapter 2: Literature Review	8
2.1 Introduction	8
2.2 Concept of Adherence	8
2.3 Importance of Adherence	9
2.4 Measuring Adherence	9
2.5 Factors affecting Adherence	10
2.6 Multifaceted Approach to Adherence	13
2.7 Disability Grant, HIV/AIDS and Antiretroviral Adherence	14
2.8 Conclusion	17
Chapter 3: Methodology	18
3.1 Introduction	18
3.2 Qualitative Research	18
3.3 Generating Qualitative Data	18
3.4 research Population Sampling	20
3.5 Data generation in details	21
3.6 Ensuring Study Validity	23
3.7 Conclusion	24
Chapter 4: Discussion of Findings	25
4.1 Introduction	25
4.2 Reasons for Disability Grant	26
4.3 Adherence Motivation and Disability Grant	30
4.4 Discontinuing the grant	32
4.5 Conclusion	35
Chapter 5: Conclusion and Recommendation	36
Bibliography	38
Appendices	42

## **Chapter 1: Introduction**

### **1.1 Problem Statement**

Since its discovery in 1981, the cumulative figure of infections due to HIV/AIDS has reached about 60 million (UNAIDS, 2009). The sero-prevalence rate for the epidemic in South Africa was 28%, and 37% in KwaZulu Natal, a province of South Africa where this research was conducted (Department of Health South Africa, 2008; UNAIDS, 2008).

The initial approach to managing HIV/AIDS was largely drug-based with discovery of Zidovudine (an antiretroviral) in 1987, which was licensed for use in HIV positive patients. This has since been followed by various combinations of Highly Active Antiretroviral (HAART) medications (McLeod & Hammer, 1992).

HIV/AIDS is categorised as a chronic illness having its treatment model similar to that of various chronic disease like cancer, diabetes and asthma. Categorising HIV/AIDS as a chronic illness also marked the shift in its social definition from an acute to a chronic illness; a shift with economic and cultural repercussions for the treatment and understanding of the pandemic at the national, local and individual levels (Barker et al, 2004; Scandlyn, 2000). With time, the HIV treatment approach has become multidisciplinary. These include among others the traditional use of antiretroviral therapy, social supports and psychological strengthening of the infected individuals. The chronic use of antiretroviral requires adherence on the part of the infected person(s). Support structures like the family, community and government exist to provide physical care and psychological motivation which in turn aid adherence (Department of Health KwaZulu Natal, 2004).

In South Africa, the government has been largely responsible for the provision of free antiretroviral medication to many of its HIV-infected citizens. Considering the possible incapacitation of such individuals by the virus, the government makes provision for disability grants to assist with good nutrition (an important factor to fighting HIV/AIDS) and transportation to the clinics. Infected individuals who could meet the laid down criteria by the government automatically become beneficiaries

(Department of Social Development South Africa, 2008). In this regard, the disability grant is aimed at facilitating patients' readiness to adhere with their medication.

Despite the availability of free antiretroviral medication and disability grants to enhance adherence, different instances of non-adherence to antiretroviral medications on the part of patients are known to occur. Conversely, these same adherence-supportive measures have been shown to be crucial for economic stability and the promotion of adherence among People Living with HIV (de Paoli et al, 2010). It is in the light of this that the small scale research was conducted to assess the influence of disability grants on HIV-infected patients with regard to their antiretroviral medications adherence.

The study was guided by the following objectives:

- i. To ascertain the extent to which disability grants (for AID-sick individuals) have been able to achieve the reason(s) for its establishment as stipulated by the governmental policy on social assistance.
- ii. To find out different ways by which disability grant has influenced people living with HIV, especially with respect to adherence to antiretroviral medication.
- iii. To assess different ways people living with HIV make use of their disability grants.

## **1.2 Method of Research**

Structured interviews were conducted for ten patients attending the Stanger HIV clinic and also for a social worker and a medical officer who regularly attend to HIV patients.

Focus group discussions were conducted for participants (volunteers from Stanger HIV clinic) in two groups. There were eight participants in each group. The interviews and focus group discussions were to allow the researcher gain better insights and wider perspectives to viewing the research topic from the personal

experience(s) of those who are directly affected and the contributions of the people who are involved in care-giving.

### **1.3 Structure of the Study**

The study is structured into five main chapters.

Chapter one briefly looks at the reason for the study and the guiding objectives. Chapter two was dedicated to reviewing of literature. This included what different literature has to say on adherence, non-adherence and disability grant in relation to HIV/AIDS and HAART adherence. Studies which were carried out on topics which have direct or indirect similarities to the research topic were also analysed in depth to allow the opportunity for relative comparison of the findings of the present research topic in a qualitative manner.

Chapter three focused on the method of research with the reasons for choosing the tools used. These included the structured interviews and the focus group discussions. The chapter also discussed the sampling approach. In chapter four findings and discussion of findings are presented. The generated data was analysed and study findings compared with the outcome of initially discussed similar studies in the literature review. Chapter five contains the conclusion and recommendation(s). The chapter tried to link together the significantly noted issues or findings (positive and negatives) in the previous chapters with the aim of making plausible recommendation(s).

## **CHAPTER 2: Literature Review**

### **2.1 Introduction**

The routine use of Highly Active Antiretroviral Therapy (HAART) has resulted directly in dramatic declines in morbidity and mortality among HIV-infected patients with advanced immune depletion. These declines occurred during an era in which antiretroviral therapies became more numerous and more potent (Palella et al, 1998). Accompanying these promises of revolutionary HIV/AIDS treatment are various significant challenges which include adherence. The chronic use of HAART unlike other non-HIV medications requires strict adherence to complicated treatment schedules (Kalichman et al, 1999).

### **2.2 Concept of Adherence**

Adherence, compliance and persistence are all terms used in literature to describe medication-taking behaviours. Adherence to or compliance with a medication regimen is generally defined as the extent to which a person takes medication by their health care provider (Adult Medication, 2006).

Adherence has become the preferred term by the World Health Organisation. It is described as “the extent to which a person’s behaviour in taking medication corresponds with agreed recommendations from a healthcare provider” (WHO, 2003). While adherence requires a person’s agreement to the recommendations for therapy, compliance on the other hand suggests a person’s passive obedience to a doctor’s order making it less favoured (Adult Medication, 2006).

Specifically, medical adherence in HIV/AIDS care refers to the ability of a person living with HIV/AIDS to be involved in choosing, starting, managing and maintaining a given therapeutic combination of medication regimen to control viral (HIV) replication and improve immune function (American Public Health Association, 2004). Adherence is not a simple issue of taking medication as scheduled; rather, it is influenced by a complex network of intertwining personal, social, environmental and cultural factors that should be considered in the development of effective interventions (Fong, 2007).

### **2.3 Importance of Adherence**

Given that adherence rate varies from study to study and the need for nearly perfect levels of adherence for successful suppression of viral load, the recorded rates of sub-optimal or poor adherence in different studies cannot be overlooked (Fong, 2007). Lack of strict adherence to HAART is considered to be one of the key challenges to AIDS-caregiver worldwide (Weiser et al, 2003). Non-adherence or sub-optimal levels of antiretroviral agents carry serious potential consequences resulting from the development of viral resistance and thus a progressive HIV disease which will lead to a higher proportion of viral load (Read et al, 2003).

For antiviral-naïve individuals, the likelihood of accumulating new mutations will increase sharply with even small departures from perfect-adherence and maximum likelihood of accumulating mutation occurring at adherence rate 60-80% (Braithwaite et al, 2006).

### **2.4 Measuring Adherence**

Researchers have used different methods to assess patient adherence to medications generally and to identify non-adherent patients. However, none of these methods can be regarded as the ‘gold standard’ (Farmer, 1999). Patients’ measurement of adherence to HAART can be assessed using these different methods. According to (American Public Health Association, 2004; Chalker et al, 2009; Miller & Hays, 2000) some of the well documented methods include

- 1) self reports
- 2) clinical assessments
- 3) pill counts
- 4) prescription refills
- 5) biological assays
- 6) medication event monitoring and
- 7) directly observed therapy

Each method is associated with its advantages and/or disadvantages. Choice of adherence measurement varies with individual researchers.

Maintaining greater than 95% adherence to HAART is necessary in order to have the greatest therapeutic impact on HIV infection. Levels of adherence below 95% have

been associated with poor virology and immunology responses (Kumar & Clark, 2005). Evidence suggests that adherence rates of between 70% and 89% are significantly associated with viral rebound and development of drug resistance (Levy et al, 2004). Compared with therapy for most other clinical conditions, HAART requires a high level of adherence for an indefinite time period to achieve optimal viral suppression (Simoni et al, 2003).

## 2.5 Factors affecting Adherence

Various factors are linked with adherence in the literatures. These factors can influence positively resulting in good adherence or otherwise, causing suboptimal or non-adherence. Some factors and possible negative aspects are shown in table 1.

**Table 1: Factors Influencing Patient Adherence: Possible Negative Aspects**

Influencing Factor	Possible Negative Aspects
Social and Economic Factors	<ul style="list-style-type: none"> <li>▪ Socio-economic problems associated with being HIV-positive including unemployment, lack of money, adequate food, housing, etc.</li> <li>▪ Stigma and discrimination against People Living with HIV/AIDS (PLWHA)</li> <li>▪ Having to travel long distances to access care and treatment or medication</li> </ul>
Healthcare Team- and Health System-Related Factors	<ul style="list-style-type: none"> <li>▪ Healthcare workers with poor understanding of the dynamics adherence</li> <li>▪ Healthcare workers with a poor understanding of the client</li> <li>▪ Stigma and discrimination from healthcare workers, not necessarily those involved in the delivery of HAART</li> <li>▪ Inability or unwillingness to engage the client as an active agent in his/her own therapy</li> <li>▪ Overworked staff with insufficient time or energy to engage the patient effectively</li> <li>▪ Disjointed approach to care and treatment – workers</li> </ul>

	<p>not working as a team</p> <ul style="list-style-type: none"> <li>▪ Poor linkages between the healthcare team and PLWHA community support groups</li> </ul>
Condition-Related Factors and Co-Morbidities	<ul style="list-style-type: none"> <li>▪ Illness-related demands</li> <li>▪ Severity of symptoms</li> <li>▪ Alcohol and other substance abuse</li> <li>▪ Psychiatric illnesses, including depression</li> </ul>
Disease Therapies	<ul style="list-style-type: none"> <li>▪ High pill burden</li> <li>▪ Difficult side effects</li> <li>▪ Complicated regimens</li> <li>▪ Poor fit between the medication regimen, patient's lifestyle, and eating pattern</li> </ul>
Patient-Related Factors	<ul style="list-style-type: none"> <li>▪ Low literacy or education level</li> <li>▪ Poor self-confidence</li> <li>▪ Lack of confidence in the physician and in the team</li> <li>▪ Poor understanding of the details of the medication regimen</li> <li>▪ Beliefs about the disease</li> <li>▪ Beliefs about the efficacy of the treatment and alternative therapies</li> <li>▪ Medication fatigue</li> </ul>

Source: (American Public Health Association, 2004)

It is important to note that achieving adherence is an interactive process and not a one-time-only event. It involves a complex process influenced by factors which are both internal and external to the patient. There is need to confront and come to terms with them. It is a dynamic and on-going process that patient negotiates each time a dose of medication must be taken (American Public Health Association, 2004). The outcome of such negotiations often gives rise to classifying the patient as either adherent or non-adherent. Education of patients about their condition and treatment is a fundamental requirement for good adherence, as is education of care-givers in adherence support technique (Kumar & Clark, 2005).

## **2.6 Multifaceted approach to Adherence**

Adherence is not only about the simple issue of taking medications as scheduled; rather, researchers have begun to respect adherence as influenced by a complex of network of intertwining personal, social, environmental and cultural factors that should be considered in the development of effective interventions (Fong, 2007). Different studies have shown that a multifaceted approach is necessary to achieve a successful treatment with HAART. This has equally significantly improved adherence (Amberbir et al, 2008; Garcia et al, 2003; Levy et al, 2004).

Basically in such an approach, individuals taking HAART need to be informed about the disease including the cause and implications for quality of life and the undesirable consequences that will occur in the absence of treatment intervention. With adequate information, if the individual involved is not motivated, therapy adherence can not be guaranteed. Motivation acts in the threshold limit of psychological disturbance. Unmotivated person(s) may fail to participate actively in self-care and adherence. In addition, there is the need to come to term with lifestyle modification as a result of the pharmacokinetics of the medications (HAART) (Garcia et al, 2003).

Support structures take different forms and may stem from the family, community, state government or non-governmental organisations (NGOs). These aim at addressing the barriers to adherence which among others include lack of financial resources, food and stigma related to disclosure of HIV status. They are critically important challenges to address if high adherence is to be achieved especially in resource-limited settings (Nachega et al, 2006).

There is a notable association between health-related quality of life and adherence to HAART. Poor adherence is commoner among those with an unstable home, low financial status and those with low medical care (Carballo et al, 2004). In some instances, individuals taking HAART routinely overcome economic obstacles to HAART adherence through a number of deliberate strategies aimed at prioritising adherence such as borrowing of transport funds to clinic to collect medication (Ware et al, 2009).

Supportive measures provided by the South African government include the provision of free antiretroviral medication and the provision of disability grants for qualifying individuals. In the past the use of HAART and its distribution was confined to resource-rich settings and developed countries, however, in recent years, the financial barriers to providing antiretroviral medications in resource-limited areas (South Africa inclusive) have decreased leading to an increase number of people accessing the HAART (Nachegea et al, 2004).

In the same vein, the South African government through the Department of Social Development (DSD) has put in place statutory policy on disability whose aim among others is to facilitate the provision of integrated social services to people with disabilities including AIDS-sick patients. The three main programmes of (DSD) into which disability must be mainstreamed as stated in the policy on disability are social security which focuses on the management oversight of social assistance in form financial grants to the poor and people with disabilities; social programmes and community development (Department of Social Development, 2008).

### **2.7 Disability grant, HIV/AIDS and Antiretroviral adherence**

According to The Social Assistance Act 2004, a person is eligible for disability grant if he or she “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 maintenance”. Figures released by SASSA (2009) showed that the disability grant accounted for the third largest social assistance grant provided by the South African government after the Child Support grant and Old Age grant.

Disability grants are available to adult South African citizens and permanent residents who are incapacitated and unable to work due to illness or disability (Hardy & Richter, 2006). Disability grants can either be temporary or permanent. If temporary, the individual will only benefit for one year and would have to re-apply while permanent grants require renewal every five years (Venkataramani et al, 2009). A number of people living with HIV/AIDS have accessed disability grants once they have fulfilled the set down criteria. Recent increase in demand for disability grants has been attributed in part to increase in number of people becoming disabled after contracting HIV with reduced immune status leading to a level where they are sick

enough to be classified “unfit to obtain by virtue of any service, employment or profession needed to enable him or her provide for his or her maintenance” (SANAC, 2008).

The disability grant is supposed to ensure that AIDS-sick patients can afford proper nutrition and transport to clinic (IRIN, 2009). This invariably serves as an indirect way of promoting adherence among individuals taking HAART. In line with this, it has been shown that individuals who are receiving HAART due to AIDS generally tend to have their health restored within space of time but such timing varies from individual to individual. Consequently, it is expected that these individuals should lose their disability grants since they are no longer too sick to work. They stand the risk of finding their health threatened again in the presence of unemployment and inadequate supports – most obviously by poor nutrition which undermines the person’s immune system and reduces the effectiveness of HAART. People on HAART need regular, nutritious meals to enjoy optimal benefits since nutrition is essential for medication adherence (Venkataramani et al, 2009; Nattrass, 2005).

Hardy & Richter (2006) carried out a study in Johannesburg to establish the preferred choice between disability grants and ARV among people with HIV/AIDS, the study revealed that majority of the grant recipients spend most of the money on food and transportation to clinics for follow-up appointments. Food takes the priority because taking a balanced nutrition is essential for ARV intake and promotion of the physical well-being. On the other hand transportation is important due to the fact that many of the recipients are poor and do not all have easy access to health facilities.

Indirectly, Hardy & Richter noted disability grant aided the adherence to ARV medications in most patients, and care-givers express concern that patients may not comply with their medications if the grant is withdrawn. However, the study further pointed out that on the part of interviewed patients, there was readiness to continue with ARV medications if the grant is withdrawn but this would be an insidious choice, since losing the grant would cause extreme hardship on the families (Hardy & Richter, 2006).

In a similar study, Venkataramani et al (2009) examined the possibility of negative effects on adherence to ARV as a result of loss of disability grants. The study sampled individuals from Khayelitsha (a suburb of Cape Town, South Africa). The findings revealed that loss of disability grants was not associated with poor adherence. It reported that of all the people interviewed not a single individual indicated the intention to trade-off grant eligibility for health. In fact, all respondents reported perfect or near perfect adherence to treatment. This Khayelitsha study by Venkataramani et al did not support qualitative and anecdotal evidence that individuals may forgo or modify treatment in order to continue receiving disability grants (Venkataramani et al, 2009). Put another way, it infers that while disability grants were made available to recipients, adherence to ARV medication was enhanced, while its withdrawal is not proven in any way to lead to fewer adherences to ARV medications.

The report on a Khayelitsha study by Natrass (2004) showed it was evident that disability grants serve as an important source of income and in fact relief for many AIDS-affected households in South Africa especially where unemployment is prevalent. This was corroborated by Booyesen (2002) who noted in a study in the Free State that there was significant difference in income between households affected and those not affected by HIV/AIDS; with the main income in affected households being government disability grants. The Khayelitsha qualitative study by Natrass quoted an interviewed participant: *“I love this HIV because we have grants to support us”* (Natrass, 2004).

By inference, such a response is a way of evaluating the extent to which grant’s beneficiaries have become dependent on the money (particularly the unemployed). Natrass further noted the possibility of a small but significant proportion of people opting to discontinue HAART so as to become AID-sick again in order to qualify once more for government disability grant (Natrass, 2004). In other words, disability grants did not promote the expected adherence per se; rather recipients have come to have a notion that it is a timely “grace” to combat the harsh-biting poverty.

While writing on ‘AIDS, Employment and Disability grants in South Africa’, Natrass (2006) indicated that many HAART patients will experience problems or difficulties

purchasing food once their grant is cancelled. This is mainly due to the fact that people on HAART need to eat regular nutritious meals and enjoy optimal health benefits. In the same vein, those who need the grants to cover transport costs to a clinic may find it difficult to access medications on a regular basis if their grant is discontinued while those depending on the grant money to pay for HAART through the private sector (in places not reached by roll-out) will not be able to continue.

Taking a closer look at the observation by Nattrass (2006) one could note that adherence as an important issue becomes indirectly compromised due to discontinuity of disability grants which serve as major play-maker to healthy living among its HIV-positive recipients.

Ndlumbini (2009) in a little study at Nyanga (South Africa) on ‘the role of disability grants in influencing People Living with AIDS to adhere to antiretroviral medications’, found that 90% of the participants believed that the grant is a motivating factor to treatment adherence while 5% reported no link between taking ARV medications and disability grants.

## **2.8 Conclusion**

Successful antiretroviral adherence programme requires the active involvement of the individual(s) affected as well as the care-givers. With the provision of HAART and adequate social supports, good adherence often emanate from motivated individuals. AIDS-sick individuals have privilege of benefiting from disability grants which is a form of social support as well as adherence motivation-inducer from the South African government.

## **CHAPTER 3: Methodology**

### **3.1 Introduction**

This chapter dwells in details on the research design and on methods used for data collection among research participants. Going by the topic, the researcher deemed it appropriate to approach the study from the point-view of *qualitative* rather than *quantitative* research. Information was gathered using structured interviews and two focus group discussions.

### **3.2 Qualitative Research**

According to Straus and Corbin (1998), qualitative research is research about persons' lives, lived experiences, behaviours, emotions, and feelings as well as about organisations functions, social movements, cultural phenomena and the interaction between nations. These authors further noted that one of the many valid reasons for using qualitative research is to explore substantiate areas about which little is known or about which more is known to gain novel understanding.

In particular qualitative research seeks to understand a given research problem or topic from the perspectives of the local population it involves (Mack et al, 2005). With the intent of having insight into what influence disability grant could have on adherence to antiretroviral medication among its recipients, the qualitative research approach is excellent. It allowed the researcher an opportunity to involve and explore information directly from individuals affected. There was better understanding of experiences and feelings among disability grant recipients with respect to adherence and related issues.

### **3.3 Generating Qualitative Data**

In the words of Mason, 'it is more accurate to speak of *generating* data than *collecting* data, precisely because most qualitative perspectives would reject the idea that a researcher can be a completely neutral collector of information about the social world. Instead, the researcher is seen as actively constructing knowledge about the social world according to certain principles and using certain methods' (Mason, 2002).

In this little study, data was generated using structured interviews and focus group discussions. The researcher asked probing questions and direct responses were captured. Data organisation was done by first reading through all the responses to allow closer familiarity. This was followed by data coding and analysis and comparison with related objectives.

### **3.3.1 The Structured Interview**

This involves obtaining answers to carefully phrased questions. Interviewers are trained to deviate only minimally from a set of given questions to ensure uniformity of interview administration (Frechtling & Sharp, 1997). The researcher conducted structured interviews for ten participants on individual basis. Such an individual must have tested positive for HIV and already be using antiretroviral medications as well as benefiting from disability grants.

A medical officer at the Stanger HIV clinics and a social worker with the South African Social Security Agency (SASSA) who regularly attend to HIV positive patients were also interviewed. Their inclusion was to allow the researcher a broader scope of insight into the topic. It also gave room for better comparison of experiences, idea and feelings. Mason (2002) noted that interviewing have some common core features which among others include: exchange of ideas by interaction, a relatively informal style and a thematic or topic-centred approach.

#### **3.3.1.1 Exchange of Ideas by Interaction**

The structured interviews were conducted individually (one-to-one) in a way that allowed interaction and two-way communication with the interviewee. Interaction began from gaining participant's consent and as necessary during the course of the interview.

#### **3.3.1.2 A relatively informal style**

From the outset of the interview, a relaxed atmosphere was ensured. This began with the use of a neutral venue separate from the regular HIV clinic and also the use of language most suitable to participants.

### **3.3.1.3 A thematic or topic-centred approach**

For ease and simplicity, the researcher made use of interview guide which contained lists of questions on the topic based on the research objectives. This was explored during each interview session. It allowed information to be obtained from each participant without any predetermined responses.

### **3.3.2 Focus Group Discussions**

Focus group discussions draw upon respondents' attitudes, feelings, beliefs, experiences and reactions. Unlike individual interviews which aimed to obtain individual attitudes, beliefs and feelings, focus groups elicit a multiplicity of views and emotional processes within a group context. It enables gaining a larger amount of information in a shorter period of time and particularly useful when one wants to explore the degree of consensus on a given topic (Gilbert, 1997).

For the research, two sets of focus group discussions were conducted – each group having eight participants. The focus group discussions further shed more light on the topic and also served as a broader means of comparing the responses with the structured interview and previous studies related to the research as highlighted by the literature research.

### **3.4 Research Population Sampling**

Purposive sampling was the sampling method used for this small scale study. According to Mason (2002) purposive sampling is the qualitative sample method used by many qualitative researchers. Hoepfl (1997) described it as the 'dominant' sampling method in qualitative research. Purposive sampling as described by Patton (2003) involved studying information-rich cases in order to gain more insights and in-depth understanding. In its general form, it means selecting groups or categories to study on the basis of their relevance to research questions, theoretical positions and analytical framework, analytical practice and most importantly based on the argument or explanation that one is developing (Mason, 2002). In this research, purposive sampling was adopted because it is the most relevant to the research topic which tried to understand the existence or possibility of any influence on adherence to antiretroviral medications by disability grant among the latter's recipients.

### **3.4.1 Sampling criteria for structured interview**

The criteria for qualifying as a participant in the interview included being an adult who has tested positive for HIV and taking antiretroviral medications. The individual must also be a recipient of disability grant. Willingness to voluntarily participate and share information and experiences is equally stressed.

The medical officer and social worker with the South Africa Social Security Agency were selected based on their involvement with managing individuals who already met with the above stated criteria. Their voluntary participation and willingness to share from their day-to-day experiences were also important criteria.

### **3.4.2 Sampling criteria for focus group discussion**

Participants in the focus group discussion had to fulfil criteria which included being an adult who had tested positive for HIV and already using antiretroviral medication as well as being a recipient of disability grant. Being a group discussion, such individuals must be ready to lose the anonymity attached with being HIV positive as a result of the participating in the group discussion. In other words, participants must bear it in mind that participation in the discussion is indirectly a way of disclosing the HIV status. Other criteria include voluntary participation with readiness to contribute and share from experiences.

## **3.5 Data generation in detail**

### **3.5.1 Details of structured interview for the ten participants**

The interview was conducted on an individual basis for ten participants who were able to meet with the criteria in section 3.4.1. It took a period of about three weeks to complete the whole interviewing process. Following informed consent, arrangement was made to meet with each interviewee at the designated venue which was separate from the general Stanger HIV clinics. This was to facilitate privacy and enhance concentration on the part of the researcher and the interviewee while the whole process lasted.

In each of the interview sessions, each participant was made aware of the need to be relaxed and to bear in mind that the whole exercise is only for research purpose. Two-way communication in form of interaction was allowed and seemingly ambiguous

questions were clarified. The questioning was done using an interview guide which allowed minimal deviation in pattern of questioning and probing of each participant. Detail notes of the responses were taken. Each interview session lasted between thirty and forty minutes at the end of which participants were thanked and allowed to clarify question(s) as related to the research.

### **3.5.2 Details of structured interview for the Medical officer and social worker**

The Medical officer who was interviewed works at the Stanger HIV clinic managing patients with HIV and related issues; while the social worker works for the South African Social Security Agency in Stanger dealing with social grant related issues.

They were willing to participate in the study and share from their experiences. Hence, following informed consent, a date and venue was set aside for the interview process which was done in the same week. Meanwhile, prior to the scheduled date, a copy of the interview guide was given to each of them to allow their familiarity with the questions and adequately prepared responses.

An interactive and relaxed atmosphere was allowed during the course of the interview proper. Having gone through the interview guide beforehand, they were able to give detailed responses and shared personal experiences wherever needed. Each of the interview sessions lasted about one hour and note-taking and tape recording were done. Each of them was thanked and given a ball-point as token of appreciation.

### **3.5.3 Details of the Focus group discussions**

Two focus group discussions were organised. Each group had eight participants. Participants' inclusion in the discussion was based on the criteria mentioned in section 3.4.2. Participation in the group discussion was purely on voluntary basis. Having earlier obtained informed consent, the researcher and group participants met at a designated venue which was a seminar room outside of the HIV clinic. The sitting arrangement was around a large round table which enhanced eye-contact and easy interactions.

Following a brief welcome, introduction and signing of the consent form, the discussion-proper commenced. The focus group discussions were anchored by the

researcher making use of sets of guide questions in accordance with the research objectives. Each question was simplified as much as possible to allow proper understanding and adequate response from participants. Each responder signifies by raising of hand and as much as possible, opportunity was given to all to speak. In each of the group discussions, participant's passivity was strongly discouraged thereby helping participants to respond freely, expressing their multiple views, opinions and feelings on various questions. Hence, this made the focus group discussion a rich source of information within a short period of time. The whole exercise lasted about seventy minutes in each group. Note-taking and tape recording were done. The researcher thanked the participants and served light refreshments.

### **3.6 Ensuring study validity**

Creswell & Miller (2000) described validity in qualitative research as how accurately a researcher's account represents participants' realities of the social phenomenon that is credible to them. There is fairly strong agreement among qualitative researchers that good qualitative research should be evaluated in terms of completeness, adequacy and trustworthiness (Cohen & Crabtree, 2006).

Several techniques for verifying qualitative accounts have been described by different authors but Cohen & Crabtree (2006) noted that many authors suggested that one or more of the techniques listed below should be integrated into the design of a qualitative study. These include triangulation, prolonged engagement, persistent observation, referential adequacy, peer debriefing, thick description, member checking, external audits, reflexivity, searching for conforming or disconfirming or deviant or negative cases and examination of rival explanations.

It may not be out rightly possible to check all the above in a single study, especially with short space of time as in this research. However, the researcher adopted the viewpoint of Creswell & Miller, (2000) which suggested that the validity of a qualitative research be viewed from three major stakes which are the researcher's lens or viewpoint (triangulation), study participants' lens (member checking) and lens of people external to the study (reviewers or readers).

### **3.6.1 Triangulation (Researcher's lens)**

Triangulation is a validity procedure where researcher searches for convergence among multiple and different sources of information to form different categories in a study (Creswell & Miller, 2000).

The researcher approached the study by gathering information using multiple methods (interview and focus group discussion). The various interviews and group discussions served as ways of comparing or corroborating generated information using multiple sources.

### **3.6.2 Member checking (Study participant's lens)**

With member checking, the validity process shifts from the researcher to the participants. It consists of taking data and interpretations back to the participants in the study so that they can confirm the credibility of the information (Creswell & Miller, 2000).

This was only fulfilled to a certain extent by the researcher. After compiling the data, the medical officer and the social worker were asked to go through the transcribed notes to comment on accuracy of the information. By this, they were able to make further inputs as necessary thereby improving the accuracy and reality of the overall account. However, member checking was not done for the other participants due to time limitation.

### **3.6.3 The audit trail (Lens of people external to the study)**

Creswell & Miller, (2000) described audit trail as “establishing credibility of a study by turning to individuals external to the project, or readers who examine the narrated account and attest to its credibility. For this study, the researcher established link with the supervisor who served as a guide as well as reviewer of the write-ups at different stages.

## **3.7 Conclusion**

In brief, attempt has been made to describe the research design and how data was generated. Using multiple methods in form of interview and focus group discussions gave room for generating data from different perspectives. A wider view to the topic

on ARV adherence has been made possible with inclusion of the care-givers (the medical officer and social worker) who are non-beneficiaries of the disability grants. Validity check was done using the triangulation, member checking and the audit trail.

## **Chapter 4: Discussion of Findings**

### **4.1 Introduction**

In the preceding chapter, it was stated that ten participants were individually interviewed (eight participants who take ARV medications, a medical officer and a social worker) and two sets of focus group discussions were conducted with eight participants in each group. The generated data from the interviews and group discussions were coded and the accumulated codes were sorted into themes. Three main themes emerged from the overall data. This chapter focuses on the details of the findings (shown as excerpts, quotes and phrases from the data) closely followed by discussions.

### **4.2 Reasons for disability grant**

Different reasons were given by participants to why the government provides the disability grants to HIV positive beneficiaries. These include mainly for the provision of food, transportation to clinics, survival strategy from unemployment and additional source of income. Here are some excerpts from their comments reflecting these perceptions:

#### **4.2.1 Food**

*“I have defaulted [treatment] because I have no money or what to eat. I think this is why government gave [established] grant.” (Focus group participant, responding in tears)*

*“This grant is established so that people will not take ARV on empty stomach.” (Focus group participant)*

*“The government gave grants to help the people that are suffering with HIV/AIDS...they will be able to buy healthy foods.” (Interview participant)*

#### **4.2.2 Transportation**

*“To have money to be able to see doctor when [I am] sick and [for] someone to be able to fetch treatment [medications] in time and not default due to financial problems.” (Interview participant)*

*“It [disability grant] was established to grant transport fare.” (Focus group participant)*

### **4.2.3 Unemployment**

*“It is important to get it [grant] because we don’t work and no support from anyone.” (Focus group participant)*

*“Yes it is relevant because the infected people are unable to get employment.” (Interview participant)*

*“Other than being HIV positive, I broke my leg in 2000 but doctor feel I should work and I can’t work. So I need grant.” (Focus group participant)*

*“We get sick more often and even the jobs you find to do you get sacked because one goes to clinic too often. Employees are strict with knowing people’s status and terminate our appointments making me jobless. So I only have the grant.” (Focus group participant)*

### **4.2.4 Additional income source**

*“It has helped me to support my brother and [pay for] funeral policy. It is a form of investment [on him] even when I am dead he can take care of others.” (Focus group participant)*

*“It will help to meet daily needs, children going to school and paying [for] funeral policy.” (Focus group participant)*

*“It is important because sometimes you have little [money] for a lot of people in the house and it’s not always enough.” (Focus group participant)*

*“Other than that [referring to previous comments by other group participants] we use it to pay for electricity, [and] help children at school.” (Focus group participant)*

The medical officer saw some relevance of the disability grant to people with HIV as a way of helping with a good diet; alleviating social problems and ultimately survival. This was in line with the comments of the interview participants and the focus group participants as earlier documented. Excerpt from the comment reads thus:

*“Relevant because some come from poor communities and taking treatment (ARV) goes with good diet. It alleviates their social problems because most of them get to a point that they can’t work; so it act as incentives for survival.” (Medical officer interviewed)*

On the same issue, the social worker was quick to note that the disability grant is relevant only to a specific group of people among the HIV positive clients but meant to support mainly for food provisions.

*“Yeah, disability grant is relevant. It is especially when they are in stage 3-4 [of the disease]. It supports nutrition [which is meant] to help their ARVS but on the flip side of the coin we see so many people who are not disabled collecting the grant.” (Social worker interviewed)*

#### **4.2.5 Discussion**

The findings of the study suggests that part of the perceived reasons for extending the disability grant to people infected with HIV by the South African government was to provide food security and transportation to the clinics. In the same vein, the foremost allocation of the grant according to the participants in the interviews and those of the group discussions was for food and transportation to clinics. This was similar to the findings of the studies by Hardy & Richter (2006) who noted that the majority of disability grant recipients spend most of the money on food and transportation to clinics. According to IRIN (2009), the disability grant is supposed to ensure that AIDS-sick patients can afford proper nutrition and transportation to clinics.

Furthermore, the study findings were able to reveal other perceived reasons for establishing the disability grant which are unemployment and to serve as an additional source of income to the beneficiary as well as the family members. Participants in the focus group discussions alluded to the fact that the disability grant has been of great support to their families especially in supplementing children school fees and paying for their funeral policies, but only a few of the participants in the interviews mentioned this.

The grant also translates to mean a relatively stable source of income for some unemployed beneficiaries. From the Khayelitsha study by Natrass, it was noted that among the 73% of the participants who had access to the disability grant, the grant contributed an average of 41% of household income (Natrass, 2004). Although this research is not a quantitative study, most of the participants particularly in the discussion groups acknowledged the grant as a source of income. In a Cape Town

study by de Paoli et al (2010), it showed that majority (98%) of HIV positives receiving grants used it to cover general (household) living expenses.

The South Africa Social Assistance Act (2004) stipulated the necessary requirements for a person to qualify for the disability grant. These, for individuals who are HIV positive would include being incapacitated by reason of the viral infection and unable to obtain the means to provide for the basic maintenance needs. It is important to state categorically that there is no special grant for being infected with HIV and testing positive to HIV is not tantamount to incapacitation (SASSA, 2009).

Obviously from the study findings, one could infer that the main purpose of giving out the grant by the documented government policy to qualified beneficiaries has been misconceived. In light of the prevailing socioeconomic conditions among many recipients one could simply term the disability grant as “survival stipends.”

In fact, taking a closer look at the comments by the medical officer and the social worker interviewed, they tend to allude to this point:

*“It alleviates social problems...so it acts as incentive for survival” (Medical officer interviewed)*

*“On the flip side of the coin, we see many people who are not disabled collecting the grant.” (Social worker interviewed)*

Apparently then, one need not wonder why the sudden rise in number of people claiming the disability grant which according to SASSA (2009) accounts for the third largest social assistance being provided by the South African government. The reason is not far fetched as it could be partly inferred from the findings of the study. Strict measures would be required to curb these ‘excesses’ which have crept into the social assistance (disability grant) system. These among others would include an enlightenment campaign and orientation or re-orientation (as the case may be) by the Department of Social Development through every possible means. These have to be focused on reasons for extending the grant to the HIV-positives and the qualifying criteria. In the same vein, there is a need to emphasise accommodating only the individuals who meet these criteria.

### **4.3 Adherence motivation and disability grant**

In line with the second objective of the research, participants in the interviews and the focus group discussions expressed their views and shared practical issues on the link between the ‘provision of disability grant and promotion of ARV adherence.’ Excerpts captured included the following positive and mixed reactions from participants.

#### **4.3.1 Positive reactions**

Responses from the participants excluding the medical officer and the social worker showed that benefiting from the grant has somehow aided the continuous use of the ARV.

*“It [disability grant] has me take [my] medications so that my grant will continue.”*  
(Interview participant)

*“I don’t feel discriminated among other people since I have everything necessary, things like food, cloth...it helped me to take my treatment accordingly.”* (Interview participant)

*“When I get the grant I eat healthy food and use my medication correctly.”* (Focus group participant)

#### **4.3.2 Mixed reactions**

Unlike the direct positive responses captured from the participants as indicated above, one participant in the focus group shared a known negative example while the medical officer and social worker had mixed feelings or reactions on the role of the grant in promoting adherence.

*“My neighbour is on the programme [taking disability grant] and uses it for local alcohol, paying debt and we are the ones who even buy him food.”* (Focus group participant)

*“At the early stage, it had negative impact because we use only CD4 count less than 200, so they do not adhere so that CD4 can become less than 200 and continue to remain qualified for the grant...when we check after six months of review and we told them of stopping the grant, majority of the noted non-adherent who are on grant tend to pick up adherence...most make effort...it has helped to reduce cigarette and alcohol consumption in some patients...so grant play a role to comply with ARV.”* (Medical officer interviewed)

*“It has negative impact in that people don’t want to lose their grant, they want CD4 to be low...yes, since many don’t want to work ...there are those who are using it for alcohol and cigarettes.” (Social worker interviewed)*

To further buttress their points on the negative impact of the grant among some patients, they commented on the issue of ‘trading-off health for disability grant’ by some grant recipients. In their words:

*“The issue is real! There was even a case being investigated here (community where the medical officer works) in the recent year of people trading [selling] their blood with low CD4 to others and put in [blood] samples to get “low CD4” and deceive the doctor in order to get grant.” (Medical officer interviewed)*

*“Yes, this is real. There are some people who deliberately trade [their health] in order to keep getting the grant...they may not be so many but there are...we get complaints, we send people (our workers) out to investigate.” (Social worker interviewed)*

### **4.3.3 Discussion**

This aspect of the research findings showed that many of the participants both in the group discussions and interviews who commented on the role of the disability grants in influencing adherence had positive experience in that it enhanced or motivated their adherence to medications. This was in line with the Nyanga study (South Africa) by Ndlumbini (2009) on ‘the role of disability grant in influencing AIDS-patients towards medication adherence’. Ndlumbini (2009) noted that majority (90%) of the participants believed that the grant serves as a motivating factor. Hardy and Richter (2006) also noted that the disability grant aided the adherence to ARV among most of the participants in the Johannesburg study.

Irrespective of the aforementioned, there were few contrary opinions which maintained the fact that the disability grant was not actually a motivating factor to some beneficiaries. Such beneficiaries were noted to spend the money on other things especially alcohol and cigarettes. Instances could be taken from the comments noted above by one of the group discussion participants and that of the medical officer. Although the research findings showed that trading-off health for the grant exists (going by the information given by the medical officer and the social worker based on

their practical experiences), the issue of ‘health trade-off’ was not the main focus of the research. However by reason of the findings, it would not be out of place to say that getting all the grant beneficiaries to be 100% compliant may not be possible since ‘pockets’ of non-compliance may exist from time to time.

The high level of HIV mortality and various negative impacts of the disease call for putting in every possible measure to stem the wave. According to Hickey et al (2003), the South African government has made provision for ARV medications in various communities and still budgets more money towards this, however, it is not enough to provide the medications when on the long run adherence will be the limiting factor. Continual provision of supportive measures part of which is the disability grant will help in sustaining adherence.

Nevertheless, it is important to observe that the grant, going by the South African government policy was meant to be temporary (if not the permanent type) and beneficiaries expected to be off the grant once their health is restored (Venkataramani et al, 2009). In most cases this has not been so. Beneficiaries often go back to review it over and over and continue to live on the money. One wonders if their so called “disability” never gets corrected and their health ever fully recovered. No doubt a state of quandary has of been created for the government (which wants to stop giving out the grant after a while) and also for the disability grant beneficiaries (who would like to continue medication adherence with continuous grant provision).

#### **4.4 Discontinuing the grant**

The issue of ‘discontinuing or stopping the grant’ was explored among all the study participants but this was met with great resistance. Negative responses pervaded the atmosphere and none of the respondents welcomed the idea. It was viewed as a form of “genocide” from the government. Part of individual comments has been highlighted below but it is worth mentioning that at the mention of ‘stopping the grant’ emotions were raised and could literally hear participants sigh heavily with an involuntary “Eish...” before talking further.

*“No, I won’t be happy at all...because millions of [us] grant recipients will have no income.” (Interview participant)*

*“No, people will die of hunger...people will default...only the disability grant make people survive.” (Interview participant)*

*“I don’t know what I will do without the grant.” (Interview participant, visibly dejected)*

*“If they [government] stop it, it will be a way of government killing people; we will die of hunger and starvation.” (Focus group participant with tear-filled eyes)*

*“It will become difficult when it is stopped. We have no support, we are not working, no money for food.” (Focus group participant)*

A participant who was awaiting grant renewal responded

*“When it was stopped my stress level [usually] go high and even to the extent to committing suicide.”*

Even the medical officer and the social worker had a similar view.

*“Stopping the grant...no they can’t! It will be a disaster because there are so many families relying on it. Don’t you know many families are poor and they have children...?” (Medical officer interviewed)*

*“I won’t say it is a good thinking...but the department of Health need to take responsibility.” (Social worker interviewed)*

#### **4.4.1 Discussion**

By policy, the provision of the disability grant is either to be temporary (renewable after 6-12 months) or permanent. This also goes for the AID-sick individuals who are expected (in most cases) to make significant health recovery, be able to provide for themselves and become independent of the grant (Venkataramani et al, 2009).

The study findings with respect to discontinuing the disability grants (temporary type) showed that such policy was never a welcome idea among the research participants and possibly many other non-participating beneficiaries too. One could infer that the money was assumed by many of them to be a life-long benefit and an alternative or relative ease to the prevailing poverty and unemployment.

Since the study was not directed at finding the relationship between ‘stopping the disability grant and the willingness to continue with ARV medications’, only the feelings and reactions that could follow discontinuation of the grant among the

beneficiaries was explored. Emotions were high when the issue of grant discontinuation was raised. None of them wanted to stop being a beneficiary. They had one reason or the other to show why they see themselves as being continually eligible for the money. It is possible to infer in this regard that poor adherence could be witnessed among such recipients if their grant was withdrawn. However studies by de Paoli et al (2010) and Venkataramani et al, (2009) showed that disability grant loss was not associated with poor adherence although this could mean a resultant hardship on the recipients. Both studies noted that discontinuing medications as a strategy to keeping the grant is not common. Both authors also found that their qualitative studies did not support the anecdotal reports of health trade-off which was contrary to the findings of this study going by the comments of the interviewed medical officer and the social worker who discussed the issue from a first hand experience that health trade-off is actually real.

With proper implementation of the governmental policy on the disability grant by the Department of Social Development, there is possibility of witnessing a reduction in the number of the beneficiaries compared with what is being witnessed presently. This could turn out to mean a reduction in the amount of government spending going into the grant which could be diverted to some other meaningful venture(s). It behoves therefore that policy makers retrace their steps and look into proper implementation of the grant among HIV positive applicants. Inasmuch ARV adherence is a key issue, abuse or overdependence on the grant should be discouraged since the grant is generated mainly from the tax-payers' money.

Stakeholders involved in promoting an HIV-free society and ARV adherence needs to collaborate and evolve programmes which are patient-centred rather than totally government-dependent. In the course of interviewing the medical officer and the social worker, it was suggested that programmes in the form of patient-empowerment rather than “dishing-out” money need to be established and focused on by the government.

*“Probably government can have a look at their list and promote entrepreneurships like baking, cleaning jobs, gardening as a pre-requisite for any money assistance to HIV positives....they (grant beneficiaries) must not see it as a free money.” (Medical officer interviewed)*

*“Department of Health need to take responsibility and people need to be made to take responsibility for their health for example gardening [on a large scale]. They need to be taught how to take responsibility while moving back to their health. This has to be a special project that is community-driven. (Social worker interviewed)*

#### **4.5 Conclusion**

From the study, the disability grant was noted as a key motivator of ARV adherence among study participants. This compared favourably with the findings from authors who wrote on a similar topic. Most grant beneficiaries spend the money on food and transportation to clinics and were not comfortable with the idea of discontinuing with the grant.

## **Chapter 5: Conclusion**

HIV/AIDS is a reality that can no longer be denied by the South African society. Addressing the myriads of problems associated with the epidemic and various impacts require a multi-pronged approach of which the provision of ARV medications and social supports play important roles.

By policy the provision of the disability grants to AIDS-sick individuals was meant in good faith to assist with adherence to ARV medication. True to this, there are many people who agreed to the fact that the disability grant has been a major boost to their surviving the scourge of HIV/AIDS. It indeed motivated the adherence to their ARV medications which is the life-line to their staying alive. Beneficiaries who participated in the study do not want government to discontinue with their grant. Withdrawing the grant from these individuals would leave many of them in hardship and could jeopardise adherence to ARV.

Many of the beneficiaries as revealed by the study findings spend the money on food and transportation to clinics. This was in line with the primary aim of providing the disability grant. The study has however revealed that beneficiaries do divert the grant money into other uses such as supporting children school fees and payment of funeral policies. In the extreme there are reported instances of grant beneficiaries using the money for alcohol and cigarettes. These inappropriate uses of the disability grant are being taken as the norm. That many of the grant beneficiaries are unemployed is another important issue that was noted in the study and this set of people has come to assume the grant as their main source of income. Putting all these together, one is likely to witness an ever increasing number of disability grant applicants in the years to come.

Again by policy, the disability grant was neither meant to serve as income for the unemployed nor was it to be the lee-way out of the prevailing socio-economic hardships among HIV positives recipients. Revisiting the implementation of the grant policy is an important issue that policy makers have to do especially as affect HIV positive recipients.

No doubt, ARV medication adherence is important but the various ‘abuse’ of the social assistance system already being witnessed need to be checked. This calls for either a strict implementation of the disability policy in terms of disability resulting from HIV/AIDS or a total overhauling of the social assistance system with the aim of providing assistance for all HIV positive individuals based on their socioeconomic status in which case the word ‘disability’ will not be applicable to them.

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## **7. Appendices**

### **7.1 QUESTIONS USED FOR THE FOCUS GROUP DISCUSSIONS AND THE INTERVIEWS**

1. Why do you think the South African government established the disability grants for people living with HIV?
2. In your own view, do you think the disability grants have any relevance to people living with HIV? Please comment in details.
3. From your own opinion, why do people living with HIV apply for disability grants?
4. Has the disability grants affected you in any way? Can you mention some of them?
5. Disability grants and the use of antiretroviral medication, do you think that they related? How? (NOTE: I DO NOT WANT TO RAISE SUSPICION, HENCE DID NOT DIRECTLY PUT IT AS “ADHERENCE TO ANTIRETROVIRAL” rather “USE OF ANTIRETROVIRAL”).
6. In what way(s) has disability grants affected or influenced your taking antiretroviral medications?
7. Do you know people living with HIV that are also receiving disability grants? What do they use the money for?
8. What concerns do you have about the disability grant?
9. If the South African government decided to stop issuing the disability grant, will you be happy? Will you be willing to stop being a beneficiary? Comment

## **7.2 INTERVIEW GUIDE USED FOR THE MEDICAL OFFICER AND SOCIAL WORKER**

1. In what ways do you think that disability grant is relevance to PLWHA?
2. In an ideal situation, do many of your clients who are HIV positive and benefiting from disability grant really qualify for it? What is or are the reason(s) for your answer?
3. Does the provision of disability grant have positive or negative impact on ARV adherence? Elucidate on your standpoint with practical examples from your experience with patients
4. From your interaction with PLWHA who are beneficiaries of disability grant, do you feel they are using the money appropriately? Share your experiences with patients in this regard.
5. ‘People trading their health for grant’ is a common anecdotal issue, do you think this is real? Briefly share your practical experience on such issue.
6. Do you get to see patients who are HIV positive but not a beneficiary of the disability grant that are adhering to their ARV medications? What really is or are their driving or motivating factor(s) to adherence?
7. What is your view on South African government stopping disability grant for HIV positive patients? Do you think this will have any positive or negative impact(s)? Explain.
8. In what way(s) can adherence to ARV medication be achieved in the absence of disability grant provision?