# SELF-REPORTED STRATEGIES FOR MAINTAINING ADHERENCE TO ANTIRETROVIRAL THERAPY IN MEN AGED 21 - 49

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# DECLARATION

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# ABSTRACT

Adherence to antiretroviral therapy (ART) is essential to maintain long term health benefits and avoid development of drug resistance. It is not possible for health care providers to reliably predict which individuals will ultimately be adherent to their treatment plan. The reason being that adherence does not correlate with gender, cultural background, socioeconomic status or level of education. Studies showed that adherence in resource-limited settings are equal or superior to that in resource-rich settings. HIV positive patients' adherence to ART is relatively high in African nations compared to developed world countries. Adherence is a multidimensional phenomenon determined by five sets of factors as set out by the World Health Organisation (WHO). The predictors of adherence are related to factors pertaining to the patient, their condition, socio-economic status, the health care system and the ART they receive. Semi-structured interviews were conducted with twelve men at a government clinic that provides ART services. The ages range from 25 to 44 years. The mean CD4 count was 294 (range 68 - 622) and all the participants had undetectable viral loads within the last six months. They were on ART for a mean 27.8 months (range 9 - 41months). Some self-strategies emerged from this study to explain the good virological response that is linked to good adherence. Participants experienced remarkable improvement in their health and physical condition and maintained good health whilst taking ART. This led to increased confidence in the ART and motivated them to stay adherent. Participants were fearful of falling ill again and of dying. Feedback regarding their CD4 counts recovering and viral loads decreasing provided them with positive reinforcement. Monthly pill counts are a strategy that gave them a sense of achievement and motivated them to maintain adherence. The participants developed specific strategies to remember to take ART. They made use of watches and cell phone alarms. Pill-taking was incorporated into their daily activities such as mealtimes, listening to radio and watching television. All the participants had an open relationship with the clinic staff. Patients at this particular clinic were well prepared by the clinic staff before starting ART. They trust the advice and instructions from the doctor and other clinic staff. The findings support the recommendations made by the National Antiretroviral Treatment Guidelines pertaining to adherence. This study emphasises the fact that patients devise their own strategies to stay adherent to ART. Each community is different and each clinic should further investigate the unique strategies that patients employ to stay adherent and build it into their treatment plan.

# **OPSOMMING**

Die nakoming van ART is noodsaaklik om langtermyn gesondheid te onderhou en om middelverwante weerstandigheid te voorkom. Dit is nie moontlik vir gesondheidsdiens beamptes om te voorspel watter individue nakomend gaan wees aan hulle behandeling nie. Die rede vir dit is omdat nakoming nie verband hou met geslag, kultuur, sosio-ekonomiese status of die vlak van onderrig nie. Studies het bewys dat nakoming in swak bediende areas net so goed of selfs beter is as in beter bediende areas. Die menslike immuniteitsgebreksvirus (MIV) positiewe pasiënte se nakoming aan ART is relatief hoog in Afrika nasies in vergelyking met die ontwikkelde nasies. Nakoming van ART is 'n fenomeen met verskeie fasette en vyf faktore word geïdentifiseer deur die Wêreld Gesondheid Organisasie (WHO). Die voorspellers van nakoming is verbind aan faktore wat verwant is aan die pasiënt, sy kondisie, sosio-ekonomiese status, die gesondheidsisteem en die ART wat geneem word. Onderhoude was gevoer met 12 mans wat ART ontvang by 'n staats fasiliteit. Hulle ouderdomme wissel van 25 tot 44 jaar. Die gemiddelde CD4 telling is 294 (wissel van 68 tot 622) en al die deelnemers het onderdrukte virale ladings gehad in die afgelope ses maande. Die deelnemers was op ART vir gemiddeld 27,8 maande (wissel 9 tot 41 maande). Daar het sekere self-strategieë na vore gekom wat die goeie virologiese reaksie wat gekoppel is aan nakoming kon verduidelik. Die deelnemers se gesondheid het merkwaardig verbeter en dit het so gebly terwyl hulle ART ontvang het. Dit het beteken dat deelnemers baie vertroue gehad het in die middels en hulle was gemotiveerd om nakomend te bly. Die deelnemers was bang dat hulle weer sou siek raak of doodgaan as hulle die ART sou stop. Die terugvoering wat hulle ontvang het aangaande hulle hoë CD4 tellings en lae virale ladings het hulle as positiewe terugvoering beskou. Die strategie van maandelikse pil telling het bygedra tot hulle gevoel van sukses en het ook gedien as motivering om nakomend te bly. Die deelnemers het spesifieke strategieë ontwikkel wat gedien het as 'n herinnering om hulle ART gereeld te neem. Hulle het gebruik gemaak van horlosies en selfoon alarms. Dit was ook geinkorporeer in hulle daaglikse roetine soos maaltye, om radio te luister en televisie te kyk. Al die deelnemers het 'n goeie verhouding met die personeel van die kliniek gehad. Die pasiënte word baie goed voorberei deur die personeel voordat hulle ART begin. Die pasiënte vertrou die instruksies wat die personeel vir hulle gee. My bevindings ondersteun die aanbevelings wat gestel word deur die Nasionale Antiretrovirale Riglyne aangaande nakoming aan ART.

Elke gemeenskap is verskillend en elke kliniek moet verder ondersoek instel in die unieke strategieë wat hulle pasiente gebuik om nakomend te bly.

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#### **1. INTRODUCTION**

Antiretroviral therapy is life-long treatment. There is no cure for HIV at this point in time.

When the National Antiretroviral Treatment Guidelines were written the National Department of Health (2004) considered that adherence to ART is essential to maintain long-term health benefit and avoid development of drug resistance. It is not possible for health care providers to reliably predict which individuals will ultimately be adherent to their treatment plan. This is because adherence does not correlate with gender, cultural background, socio-economic or education level. Nor does it correlate with language barriers between provider and patient.

It is quite apparent that adherence is a very complex combination of many different factors. Treatment regimens are very complex and strict adherence to ART is required to achieve viral suppression, recovery of the immune system which ultimately equates to better outcomes and decreased morbidity and mortality. An adherence rate of more than 95% is necessary to achieve viral suppression because of the rapid replication and mutation rate of the virus (Paterson, Swindells, Mohr, Brester, Vergis, Squler, Wagener & Singh, 2000). This seems a very daunting task as patients on other types of chronic medicine have reported adherence rates averaging 50% (WHO, 2003).

Poor adherence can also lead to public health implications. Resistance to ART can be transmitted from one person to another during high risk activities which limits treatment options for the newly infected person. Wallis, Bell, Boulle, Papatanasopoulous, Venter, Sanne and Stevens (2007) found that 80% and 61.5% of patients in two different clinics in South Africa harboured viruses with ART drug resistant mutations.

At the moment in the government sector there are only two regimens available. The cost of the first regimen starts at about R88 and the cost of the second regimen is R557 per month. (Prices obtained from Chief Pharmacist, HIV/AIDS Directorate, personal communication). If the patient is adherent, it is possible to stay on the cheaper, first regimen for many years with good outcomes. If adherence is not good, resistance to the ART can develop and patients can quickly fail the first regimen and will have to move on to the much more expensive second regimen. If patients fail the second regimen, they are left to deteriorate as there is no third regimen available currently.

The National Antiretroviral Programme has not achieved their target for enrolling the required amount of patients onto the programme and many clinics have long waiting lists. The National Department of Health stated in their report to the United Nations General Assembly Special Session (UNGASS) for the period January 2006 to December 2007 (submitted in February 2008) that in 2007, 889 000 people needed treatment of which 488 739 (55%) enrolled and 371 731 (42%) initiated on the public ART programme. The Actuarial Society of South Africa uses available data up to 2003 to make various projections. On the assumption that by June 2008, 495 000 people will be receiving ART, the model estimates that at that time, 520 000 people in need of treatment will not be receiving it.

The longer a patient can stay on the first regimen, the more funds are available to enrol new patients onto the programme. This can assist in alleviating the growing health care burden on the government sector. Because of the great importance of adherence to ART, good strategies for maximising adherence are essential.

Studying the strategies that adherent patients apply may provide important information about attitudes, beliefs and behaviours that lead to optimal adherence.

The national guidelines for the use of ART were developed in order to ensure optimal therapy and good clinical outcomes. The guidelines formed part of the response to the HIV epidemic guided by the Strategic Plan for HIV and AIDS and the Comprehensive Plan for the Management, Care and Treatment of HIV and AIDS in South Africa. The approach that has been adopted is that of the continuum of care, with a holistic patient focus in an integrated health care system (National Department of Health, 2004).

The National Department of Health (2004) in the National Antiretroviral Treatment Guidelines, acknowledges the fact that adherence to ART is complex and are influenced by many factors. The guidelines make recommendations on specific systems that need to be in place to ensure good adherence to ART. Internationally there are also best practice models advising on ways to improve adherence. South Africa is unique in many aspects of the HIV/AIDS epidemic regarding HIV prevalence rates and regionally the differences are also apparent. We are not aware of all the factors that encourage good adherence.

What are the factors associated with good adherence as reported by a group of men aged 21-49 on antiretroviral therapy with suppressed viral loads? The outcome of this study will be very important to the patients at this clinic, the clinic staff and the clinical team responsible for the roll out of the National Department of Health's ARV programme. New and novel strategies employed by the patients to increase and sustain their adherence levels can serve as a tool to assist existing patients struggling with adherence and guide new patients. These strategies can also be integrated into the existing guidelines on adherence as recommended by the National Department of Health.

The aim of the study is to identify factors associated with good adherence in men aged 21 to 49 in order to improve levels of adherence by incorporating and implementing these factors in treatment adherence programmes.

# Objectives:

- To assess the treatment adherence programme at the clinic based on the National Antiretroviral Treatment Guidelines (2004).
- To identify the factors encouraging adherence.
- To identify the gaps between the factors encouraging adherence and the treatment adherence programmes.
- To make recommendations on how to amend the treatment adherence programmes if necessary.

# 2. LITERATURE REVIEW

# 2.1 Burden of the disease

HIV is among the leading causes of death worldwide and causes more deaths than any other infectious disease. In 2007 worldwide, the number of adults and children living with HIV was estimated at 33.2 million with 2.5 million new cases that year and 2.1 million HIV-related deaths. Sub-Saharan Africa comprises over two thirds (22.5 million) of the people living with HIV/AIDS and seventy six percent of HIV-related deaths worldwide (UNAIDS, 2009).

HIV remains a disease of the young, working class population. In 2009, people aged 15-49 years had a prevalence rate of 18.8% and comprise 87% of the total infections (Statssa, 2003).

The World Health Organisation in 2007 estimated the life expectancy of males and females in South Africa to be 52 and 55 years respectively.

HIV/AIDS increases morbidity and mortality in populations at certain ages where rates of morbidity and mortality are normally low. These events lead to other impacts which can either be immediate or have a long-term effect. The impacts will also occur at different levels namely households, communities and nations. Poorly resourced households and communities will have trouble coping with the loss of a breadwinner and there might be an immediate decline in living standards (Barnett & Whiteside, 2002). HIV aggravates poverty as the income of the affected household declines. Bachmann and Booysen (2003) found that households affected by HIV/AIDS were substantially poorer, larger and had lower employment rates.

New forms of households are emerging because of the impact of demographics. Households headed by grandparents or the elderly and households headed by orphans are a common phenomenon (Barnett & Whiteside, 2002). The General Household Survey indicates that in South Africa in 2007 there were approximately 3.7 million orphans and is equivalent to twenty percent of all children in South Africa (Statssa, 2003). UNAIDS reported that 1.8 million new orphans lost parents to AIDS in 2007.

Barnett and Whiteside (2002) also describe how care of the elderly is being neglected and poverty remains a stark reality for these households who often have to get by on minimal social grants. Under normal circumstances the adult will look after the child, share knowledge and act as a mentor. In later years, the child will in turn care for the elderly parents. The HIV epidemic wipes out the adult population leaving the child stunned and the elderly neglected.

Similarly it affects the working class population in different sectors. A critical loss will be that of health care workers in the face of the epidemic. It will impact on society as a whole as the capacity of health care services will be greatly diminished despite the fact that the demand for health care services are growing. Five percent of health care workers will have HIV and ten to eighteen percent of health care workers will have died from all causes of death and AIDS attributed to increased numbers of death (Steinberg, Kinghorn, Soderlund, Schierhout & Conway, 2000). Shishana, Hall, Maluleke, Chauveau and Schwabe's (2004) estimations looked even bleaker. They estimated that 15.7% of health care workers employed in the public and private health facilities in four South African provinces were living with HIV/AIDS in 2002. This impact will be felt severely because the younger health care workers have a higher prevalence rate. The prevalence rate in the age group 18 – 35 years was higher

at twenty percent. In the absence of any interventions, South Africa can be expected to lose sixteen percent of its health care workers in the future.

The education sector also bears the brunt of the disease. Teachers and support staff are not exempt from the wrath of the HIV epidemic. The South African Democratic Teachers Union (SADTU) reported that death among teachers increased by forty percent from 2000 to 2001. The average age at death was 39 amongst a total of 10111 teachers. The figures are based on claims submitted to the SADTU's funeral scheme between June 2000 and May 2001. The union represented more than 216 000 teachers at that stage (Govender, 2001). Education faces both supply and demand impacts. Students with special needs are emerging like orphans, HIV infected children and children who are being discriminated against because of their association with HIV/AIDS. The death of a teacher has a serious impact because it affects the lives of a classroom full of children. In an environment with a high prevalence rate teachers will be difficult to replace. Even more so if key role players like principals are lost (Barnett & Whiteside, 2002).

HIV/AIDS has just as huge an impact on businesses in Southern Africa. The mining company, Debswana is often used an example when it comes to describing the impact of HIV/AIDS. Debswana experienced a significant high percentage of ill-health retirement of up to 75% during 1999 that was AIDS-related and 59.1% of all deaths were AIDS-related. Without any interventions, Debswana's workforce would have been wiped out by now which would have affected the mining industry and also the economy of the country where they were operating from negatively (UNAIDS, 2002). Large pools of unskilled workers are shrinking at an alarming rate and the skilled workers are difficult to replace as few people have acquired these skills in time to replace others.

Consumers buying patterns are also changing. A large furniture retailer studied the potential impact of HIV/AIDS on their consumer market and found that in the absence of any interventions the client base will decline by 18% in 2015. High mortality rates will force consumers to reallocate funds (Whiteside, 2001).

UNAIDS reported in 2009 that ART coverage in Southern Africa rose from seven percent in 2003 to 44% in 2008 for those people in need of ART. The rapid expansion of access to ART is helping to lower AIDS-related deaths in many countries. The National Strategic Plan (NSP), a multisectorial response to South Africa's AIDS epidemic call for treatment and care

for 80% of HIV positive people by 2011. In 2007 an estimated 28% of infected people in South Africa were receiving treatment for HIV (www.avert.org).

Non-adherence to ART predicts progression to AIDS, after CD4 count. Consistently high levels of adherence are important determinants of virological and immunological outcome, AIDS-related morbidity and hospitalisation. Non-adherence risks the development of drug resistance and failure to treatment (Hogg, Heath, Bangsberg, Yip, Press, O'Shaugnessy & Montaner, 2002).

# 2.2 The effectiveness of interventions to improve adherence to ART

The meta-analysis performed by Simoni, Pearson, Pantalone, Marks and Crepaz (2006) showed that various adherence intervention strategies were successful, but more research is necessary to identify those components of the interventions that are most efficient. In the majority of the studies (55%) the delivery method of the intervention was one-to-one counselling. The studies that included didactic information dissemination and interactive discussion regarding cognitive behaviour tended to have larger effect. Simoni et al. (2006) warns that these results should be viewed in light of the fact that many studies used multiple intervention components. Chesney (2000) found that interventions did have a positive effect on adherence. Interventions tailored for specific age groups were very successful for example assessing the barriers to adherence for adolescents and setting alarms as a reminder to themselves. Chesney concluded that the major factors associated with poor adherence in the group of adolescents are patient-related and strategies designed to address patient behaviour have improved adherence.

Weber, Christen, Schopp, Znoj, Schneider, Schmidt, Opravil, Gunthard, and Ledergerber (2004) achieved improved maintenance of adherence to ART over a twelve month period. Cognitive behaviour interventions were applied on an individual basis.

There are also effective adherence interventions without a theoretical explanation of the mechanism of action. Technical interventions which include pill boxes and reducing pill burden were very successful and also behavioural interventions that included memory aids and incentivised programmes (Van Dulmen, Sluijs, Van Dijk, De Ridder, Heerdink, & Bensing, 2007).

#### 2.3 The predictors of good and poor adherence

Adherence is a multidimensional phenomenon determined by five sets of factors, termed "dimensions" by the World Health Organization (WHO, 2003). The studies on adherence provide us with a wealth of information and in this way we can warn patients to avoid situations we know will negatively affect adherence. There are five dimensions that have been identified and these are related to adherence.

#### 2.3.1 Socio economic

South Africa is classified as a middle-income, developing country and until the turn of the century it was considered financially impossible to provide ART on a large scale. There have always been concerns about adherence issues in patients living in poverty and this has been an important consideration in expanding access to ART in sub-Saharan Africa. Mills, Nachega, Bangsberg, Singh, Rachlis, Wu, Wilson, Buchan, Gill and Cooper (2006) found the opposite that adherence may not be the challenge once predicted in sub-Saharan Africa and acceptable levels of adherence can be achieved. Orrell, Bangsberg, Badri, and Wood (2003) came to the same conclusion that socio-economic status had no impact on adherence and these types of assumptions should not be used to limit accessibility to ART.

In a resource limited setting, 88 % of patients achieved more than 95% adherence (Nachega, Stein, Lehman, Hlatshwayo, Mothopeng, Chaisson & Karstaedt, 2004). Coetzee, Boulle, Hildebrand, Asselman, Van Cutsem and Goemaere (2004) also found that in another resource limited setting a substantial portion of patients achieved viral load suppression with outcomes comparative to adherence rates in developed countries. High rates of adherence on a homebased care programme in Uganda were achieved (Weidle, Wamai, Solberg, Liechty, Sendagala, Were, Mermin, Buchaz, Behumbiize, Ransmon, & Bunnell, 2006).

People overcome financial barriers to adherence by adopting certain strategies like borrowing and allocating resources in favour of treatment, often having to choose between food and HIV care. Adherence is made a priority by requesting and accepting help and support from social networks (Ware, Idoko, Kaaya, Biraro, Wyatt, Agbaji, Chalamilla & Bangsberg, 2009).

Social support is the physical and emotional comfort given to us by our family, friends, coworkers and others (<u>http://www.wikipedia.org</u>). One website described four components of social support: emotional, appraisal, informational and instrumental support. Instrumental support refers to a direct or practical component (<u>http://www.euphix.org</u>). Williams (2007) identified that patients utilise support groups for informational support, receiving advice on healthy living, ART information and accessing treatment. Friends and family members were the main source of emotional and instrumental support in the form of food and transport fares. No association between social support and adherence were documented most probably because the study population was over represented by patients who are coping well on ART.

Dimatteo (2004) found patients receiving practical support for their treatment regimens demonstrated a strong relationship with good adherence compared to emotional or undifferentiated support. Issues with adherence exist for HIV-infected children and vulnerable adults dependent on a caregiver for administering ART. Practical support is essential in these cases as adherence is only as good as what the caregivers can achieve (Chesney, 2000).

In some instances social support is associated with less negative affect and greater spirituality which in turn leads to self-efficacy to adhere (Simoni et al, 2006).

#### 2.3.2 Health care systems

An active partnership with the health care provider, trusting the health care provider and continuity of care were all indicators for good adherence (Golin et al., 2002, Lewis et al., 2006).

Higher quality patient-provider relationships are associated with better adherence. Multiple dimensions of the patient-provider relationship are associated with medication adherence in people with HIV (Schneider, 2004; Beach, Keruly & Moore, 2006). A good relationship can be a motivating factor for adhering to treatment. Patients who had a negative experience with a health care provider in the past might decide to avoid the health care system for HIV care. Perceptions of the competence of the health care provider, quality of communication, compassion, being accessible and treating the patient as a partner in the decision making process are all factors that strengthen the patient-provider relationship. Providers also experience a sense of frustration if patients do not honour appointments, are non-adherent or presents with side effects. It is clearly a two-way relationship and patients should be treated as equal partners and be involved in every step of the decision making process (Chesney, 2006).

Patients who were discriminated against by health care providers because of gender, race or socioeconomic status were less adherent to ART and were less satisfied with the health care provided (Bird, 2004).

Johnson, Chesney, Goldstein, Remien, Catz, Gore-Felton, Charlebois and Morin (2006) suggested that adherence self-efficacy is the mechanism of the relationship between health care provider and medication adherence and the pattern was the same for all groups; gender, race and drug use. Johnson and colleagues went on to make suggestions how to foster this relationship and identified possible areas for change. Structural changes within the facility to allow more time with a patient, developing the provider's skills (negotiating and motivating) and the patient's skills (stress management and communication).

#### 2.3.3 Condition related

Patient's beliefs about disease and medication plays an important role in their intentions to be adherent. The Health Belief Model has been frequently used as a theory to explain and predict adherence to medical care instructions. Using this model to assess HIV positive patients' beliefs regarding HIV/AIDS and ART can provide insight into treatment adherence (Gao, Nau, Rosenbluth, Scott & Woodward, 2000). Gao and colleagues measured the relationship between disease severity, health beliefs and adherence to medication among HIV patients in three different stages of HIV/AIDS. Patients who experienced more complications perceived a stronger link between non-adherence and disease-related complications and were more adherent to their treatment regime when compared to patients with no prior complications. Weight gain is a symbol of good health and can affect adherence further down the line (Castro, 2005). A more complex regime with higher pill burdens were also associated with increased disease severity and in turn increased adherence to treatment. Nachega et al. (2004) also found that the devastating effects of HIV/AIDS were a significant predictor for good adherence. Orrell et al. (2003) on the other hand found that the clinical staging of HIV at commencement of treatment did not predict adherence, but rather the fact that there is no alternative therapy available.

Government HIV programmes strictly adhere to the criteria guiding physicians on commencing ART. To provide ART to as many deserving patients as possible the CD4 count is used as one of the starting criteria. The South African Guidelines use a very low CD4 count of 200. This type of criteria can also create the impression that one is only truly ill and will

benefit from treatment when these criteria are met. A lower belief about the necessity for ART initiation leads to non-adherence (De Boer-van der Kolk, Sprangers, Ende, Schreij, Wolf & Niuewkerk, 2008). While new literature is suggesting starting treatment at a much higher CD4 count even in the absence of complications, it might take more convincing and preparation to overcome the principles of the Health Belief Model in these situations (Kitahata et al., 2009). Better health at the commencement of treatment can lead to poorer adherence.

#### 2.3.4 Treatment related

Complexity of treatment is known to be a major factor influencing adherence and it decreases as the complexity of the regimen increases, for example the amount of tablets and frequency of dosing, requirement of food or dietary requirements (Glass et al., 2006; WHO, 2003; Golin et al., 2002).

Claxton, Cramer and Pierce (2001) compared compliance to once daily, twice daily, three times daily and four times daily dosing regimens. It was found that compliance on a once daily regimen was higher than the average rates of compliance. Compliance decreased as the number of daily doses increased, but there was no difference in compliance between once daily and twice daily regimens. A three times daily regimen was found to be the strongest predictor for non-adherence (Orrell et al, 2003).

Adherence decreases as the complexity of the regimen increased. A higher pill burden may put patients at risk for non-adherence. Evidence from this particular study suggested that patients on a non-nucleoside based regimen (lower pill burden) may be at a lower risk for non-adherence compared to a protease inhibitor based regimen (high pill burden and dietary requirements) (Glass et al., 2006). Difficulty of the dosing regimen and running out of treatment was two of the top three reasons for missing doses (Nachega et al., 2004). It was found to be essential to tailor the ART regimen to fit one's lifestyle (Lewis et al., 2006).

Side effects can adversely affect adherence (WHO, 2003) and patients with more than one side effect are less likely to adhere to ART than other patients (Stone, 2001). Cote and Godin (2005) on the other hand found that the presence of side effects does not predict adherence, but rather one's attitude toward ART and the ability to take is as prescribed. Side effects can be transient or longer lasting. Certain antiretroviral drugs cause metabolic changes and change the shape of the body (lipodystrophy). This side effect has been shown to negatively affect

adherence (Castro, 2005). Body changes have been noticed by family members, friends and members of the community and patients are often stigmatised or forced to disclose their HIV status. This can lead to depression and can influence relationships. Lipodystrophy affects a patient's quality of life and can lead to discontinuation of ART (Guaraldi, Murri, Orlando, Giovanardi, Squillace, Vandelli, Beghetto, Nardini, De Paola, Esposito, & Wu, 2008). Hawkins (2006) found that 36.2% of patients discontinued treatment due to lipodystrophic changes. The literature has indicated that optimal adherence occurs with medications that remove symptoms, whereas adherence is reduced by medication that causes side effects (Chesney et al., 2000).

Stone et al. (2001) also stated that one should intervene to enhance the adherence of all patients before problems develop and will increase the likelihood of early treatment success for the patients who receive ART. Alcohol use in patients taking ART is a good example. Kalichman, Amaral, White, Swetsze, Pope, Kalichman, Cherry, and Eaton (2009) found that patients on ART believed alcohol and ART should not be taken together as it may be toxic. As a result, patients who consumed alcohol temporarily stopped their medication to avert possible adverse effects. This category of patients can be identified prior to starting ART and can be educated about the necessity of taking ART continuously even if they are drinking alcohol.

Food-drug interactions or dietary requirements influence adherence to a great extent, especially in resource limited settings where food security is a problem. Some patients have reported skipping doses when no food was available (Castro, 2005; Halkitis, 1999). Some medication needs to be taken on an empty stomach. This poses a problem to the patients as many may feel sick when taking treatment on an empty stomach and also end up skipping doses or taking it with food which might influence the absorption of the drug (Cote et al., 2008). O'Brien, Clark, Besch, Myers and Kissinger (2003) found gastrointestinal events the most common reason for a patient to stop ART.

In areas of high poverty rates and limited health care facilities where transportations to health care centres may be a problem, it is necessary to come up with innovative ideas to overcome these obstacles. Weidle et al. (2006) had great success improving adherence in a rural community with a home-based AIDS care programme with limited access to health care services. Trained lay people visited patients regularly to deliver medication and to collect relevant information. Only 2.6 % of patients had an adherence rate of less than ninety five

percent. Another intervention base on the directly observed therapy (DOT) programme used in South Africa for patients receiving treatment for tuberculosis, proved to be a success. Bradley-Ewing, Thomson, Pinkston and Goggin (2008) found a modified form of DOT, mDOT to be effective in improving adherence.

# 2.3.5 Patient related

A patient's behaviour is the link between prescribed treatment and outcome. The regimen might be simple, causing no side effects. All the other predictors of good compliance might be in place, but if the patient refuses to take treatment, it cannot be forced on them. Patients' perceived self-efficacy to take ART was high when their beliefs about ART were positive (Golin et al., 2002).

Patient-related issues are the most important factor that affects adherence. Thirteen out of thirty barriers identified by Mills et al. (2005) were patient related and included issues like fear of disclosure, forgetfulness and having a concurrent disease. Weidle et al. (2006) came to the same conclusion. Being away from home, also ranked as a number one reason for missing doses. An explanation could be that in an area with high unemployment rates people are mostly away from home looking for work (Nachega et al, 2004).

In different studies certain situations were repeatedly identified to interfere with levels of adherence. Being too busy or forgetting, being away from home, or having a change in their daily routine were the three most commonly reasons for missing doses (Golin et al., 2002).

Younger age proved to be a barrier to good adherence (Glass et al., 2006, Orrell et al., 2003; Schneider, 2004) and that is why it is important creating individualised tools for maintaining adherence (Lewis et al., 2006).

Psychosocial issues can interfere with adherence. Patients who abuse alcohol are significantly less adherent to ART and current active drug users are also associated with suboptimal adherence (Golin et al., 2002). Psychiatric co-morbidity and depressive illness is also predictors for adherence. Patients who did not have depressive symptoms were two times more likely to be adherent than depressed patients and patients with psychiatric co-morbidities had one and a half times greater risk of terminating treatment earlier (Amberbir et al., 2008; Schneider, 2004; Edward et al., 2006).

Lower literacy levels have been cited to worsen adherence presumably because treatment recommendations needed to be understood, but other studies suggested that this is not true Golin et al. (2002) and Pinogne and Dewalt (2006) concluded that low literacy is not associated with poor self-reported adherence to medications and patients initially may have difficulty learning ways to be adherent, but can overcome these barriers over time with ongoing support.

Social support can act as a buffer for psychosocial issues. It is not a predictor of adherence, but rather one's attitude toward ART and the ability to take it as prescribed (Cote et al., 2005).

Philosophical analysis should also be considered to identify mechanisms of adherence. The two models that have been identified is the principle of continence which advice us to act after having considered everything. The second principle of foresight tells us to give priority to the future. People who do not have future goals or is concerned about day-to-day survival instead will not be seeking long-term rewards and will have poor future adherence (Reach, 2008).

A person's beliefs and understanding of HIV and ART can influence adherence. Gao et al. (2000) found an intention to be adherent to ART in patients who believe HIV/AIDS is a serious disease and non-adherence can lead to worsening of symptoms. Identifying beliefs that act as obstacles to adherence and programme success is crucial. Mitchell, Kelly, Potgieter and Moon (2007) gathered evidence on perceptions of the South African government's ART rollout programme. They found a lack of accurate knowledge about HIV/AIDS and misconceptions about ART, such as ART not being superior to other forms of therapy. This can seriously affect adherence rates. Wenger, Gifford, Liu, Chesney, Golin, Crystal, Berry, Coplan, Bozette and Shapiro (1999) and Viswanathan, Anderson and Thomas (2005) found better adherence in patients who believed ART to be effective and had positive attitudes towards ART.

#### **3. METHODOLOGY**

A qualitative study was conducted using semi-structured interviews and a document analysis. The target population was men at an ART clinic in the Western Cape. They were selected using the following criteria: males aged 21-49 with a suppressed viral load on ART as determined by a blood test within the last six months. The participants resided in the informal

settlement that the clinic serves and attended the clinic on a monthly basis for pharmacy refills and medical check-ups.

The group consists of 12 participants. Data was collected by conducting semi-structured interviews to determine strategies utilized to ensure ongoing adherence to ART and then to compare these to those recommended by the National Antiretroviral Treatment Guidelines. A document analysis of the contents of the National Antiretroviral Treatment Guidelines pertaining to adherence was conducted to establish what the current treatment adherence programmes at the clinic involves.

The measuring instruments included an interview guide designed for this study that identified the factors encouraging adherence to ART. The analysis of the data from the semi-structured interviews was used to identify themes within the different factors encouraging adherence. The document analysis identified the guideline recommendations and how this compared with the identified factors encouraging adherence. Permission was obtained from the Ethics Committee of University Stellenbosch and the Western Cape Department of Health for the clearance of a new research project. Informed consent was sought from the participants before conducting any research.

#### 4. **RESULTS**

#### 4.1 **Participant characteristics**

A total of 12 participants were interviewed: one Coloured man and eleven Black men. Their ages ranged from 25 to 44 years. The typical participant was unemployed; only two participants had low-income work. Literacy levels were low and most participants did not complete school. A total of eleven participants (91.7%) were on a first line regimen and one participant was on a second line regimen. The first line regimen consisted of Stavudine, Lamivudine and Efavirenz. The second line regimen consisted of Zidovudine, Didanosine and a protease inhibitor called Aluvia. Five participants (41.7%) had been on medication for over three years. Participants had been taking ART for a mean of 27.8 months (range 9 to 41 months). All the participants had undetectable viral loads within the last six months. All participants gave written consent.

#### 4.2 Socio-economic status

Franschoek is a farming community producing a variety of fruit and wine. The study participants came from the Franschoek area with the clinic situated in Franschoek North. Most people in this community find seasonal work on the farms for minimum wage. There is little formal housing. There are low literacy levels and a high incidence of poverty.

Eleven of the participants (91.7%) complained about the financial insecurities they experience. However, no participant complained that this was affecting their ability to stay adherent. It remained a concern because they did not always have money to cover the daily living expenses.

Participants were very selective about whom they disclosed to. All the participants disclosed to someone they lived with, but did not disclose to those family members and friends they thought would not accept the fact that they are HIV positive. These people were perceived as not being able to provide positive support. Participants indicated that the people they disclosed their HIV status to and disclosed the fact that they were taking ART, were very supportive to the extent that they enquired about their health and well-being and not necessarily assisted them with their adherence.

Eight (66%) of the participants had wives or girlfriends who were also HIV positive and four of them were taking ART themselves. The participants felt that having a partner who is on ART was a positive support. Patients with higher levels of social support from partners demonstrated higher rates of medication adherence (Hamilton et al, 2007). One participant, whose girlfriend started ART before him, said that she was a great source of information and they could talk about the treatment. This assisted him in staying adherent as they also reminded each other of the time to take their treatment even though their routines were different. There is a HIV support group in the area. None of the participants were aware of it and only one participant commented that it seemed like a good idea. One third of the participants had the support of a HIV positive partner who was also on ART which could lead them to think that joining a support group was not necessary.

The participants could not give an example where they were discriminated or stigmatised against because of their HIV status or the fact that they are taking ART. The fear that they will not be accepted or talked about in a negative manner was very real to them. The two participants who worked and took their ART doses at work sometimes did so in front of colleagues and did not tell them what it was for or lied about it. Nachega and colleagues (2004) and Mills and colleagues (2006) found that the fear of stigmatisation may cause patients to hide their ART or skip doses in the presence of others. By not disclosing the fact that the medication they were taking was in fact ART, there existed no reason in their minds to be discriminated against.

#### 4.3 Health care system effects

The clinic at which the study was conducted was well resourced. There were 120 patients on ART. The staff complement consisted of one medical doctor, one nursing sister, one nurse and three lay counsellors. The lay counsellors were very active in the community and did home visits on a regular basis, prior to starting ART and monthly for the first few months. This assisted the counsellors in identifying and addressing any problems early. Each lay counsellor had a certain amount of patients assigned to him or her that they were responsible to follow up. They also conducted HIV-related lectures at the clinic. They proudly told the researcher that they know each and every patient's story and participants showed appreciation for this type of open relationship. All the participants trusted the clinic staff and had the courage to approach them with any concern.

The current government guidelines state that someone are eligible to start ART when the person presents with a stage 4 condition (WHO, 2008) or if the CD4 count is below 200 cells. Once the patients fall into this criteria they attend a minimum of two counselling sessions with the lay counsellor who provides information about the treatment, side effects, how to manage side effects and the issues surrounding adherence. Any myths about HIV get dispelled during these sessions as well. The patients have to provide the name and relationship status of a person that they disclosed to and also appoint a treatment buddy. A treatment buddy assists the patient with adherence, will contact the clinic if the patient falls ill or cannot attend and will collect the patient's ART on his or her behalf if the patient has previous commitments. Initially, the counsellors also visit the patients at their homes to assess the living conditions and to assist with adherence in their specific environment.

The clinic staff also played a big role when it came to information dissemination. They provide HIV and ART-related information, do adherence checks and continuously follow up the patients. Adherence counselling is an ongoing aspect of the ART programme at this clinic and is reinforced by the medical doctor as well as the supporting staff members. There exists a high degree of trust between the clinic staff and the participants. One patient commented,

without reservation, that he will never stop his ART until his doctor tells him to do so and he is prepared to continue taking ART because his doctor told him it is life-long treatment. Doctor-patient relationships have been said to affect rates of adherence. Some studies conducted in the developed world countries found that patients changed doctors if they did not feel comfortable or did not trust a specific doctor (Schneider et al, 2004). In the government ART roll out programme this luxury does not exist and patients learn to cope with this. They often build relationships with other members of the healthcare team that they trust. Overall, the participants experienced this particular clinic as a positive support system.

#### 4.4 Condition related effects

General wellbeing, becoming healthy, maintaining good health and ultimately staying alive were key strategies in sustaining good adherence. The participants attend a government clinic and the current guidelines state that a person can start ART when the person presents with a stage 4 condition or if the CD4 count is below a certain level. Naturally, most of the participants were very ill and were enticed by the promise that ART will improve their condition.

Half of the participants had to start ART because of a debilitating opportunistic infection. Half of the participants had tuberculosis at the time they started ART. They could recall their experiences quite vividly and experienced the devastating effect of HIV. They were able to compare their condition before ART to their improved, healthy condition after starting ART. This gave them confidence in ART and was a clear motivation to stay adherent. Orrell et al. (2003) found that the clinical staging of HIV at commencement of treatment did not predict adherence, but rather the fact that there is no alternative therapy available. All the participants had a good idea what a CD4 count and a viral load were. The remainder of the participants who did not present with an opportunistic infection at initiation of therapy, could explain that the reason they had to start ART was because their CD4 counts were low. The only way to increase it was by taking ART.

Being HIV positive and having a ravaging opportunistic infection like tuberculosis caused most of the patients to lose a lot of weight. After starting ART and as the tuberculosis improved, participants explained that they started picking up weight again. This perceived positive effect was linked to ART and ensured adherence to ART.

#### 4.5 Treatment related factors

In the government ART roll out programme, treatment regimens are dictated by the National Department of Health. There is limited amount of drugs available in the ART programme and thus very little room for manoeuvring. It is possible to switch drugs if a side effect occurs, but impossible to construct a once a day regimen with a low pill burden. Eleven out of the twelve participants (91.7%) were still on a first line regimen with a fairly low pill burden, five tablets a day. A typical second line regimen consists of ten tablets a day. All of the participants were on a twice a day regimen and did not mention that the frequency of dosing or the pill burden was an obstacle to adherence. Other studies that looked at complexity of regimens as an obstacle to adherence often saw the patients on regimens that had food requirements and three times daily dosing (Glass et al., 2006; WHO, 2003; Golin et al., 2002).

The regimen could not be reduced in frequency, but participants quite quickly developed their own routine. The participants were directly questioned about the strategies and aids they used to assist them in taking the treatment at the correct time each day. Some strategies that were developed included taking medication when a certain television programme was on every day. Another participant explained that he took his treatment at work after they received breakfast each morning.

Participants even devised their own strategies when they were away from home. One participant described how he counted out the amount of tablets that he would need while he is away. He would put it in a little bag and take it with him. A few participants also described making use of this strategy when working late and will take their medication at work.

All the participants indicated that their circumstances and daily routines are major strategies which involve planning ahead for the day or longer time periods if they knew they were not going to be home.

When asked how they remember to take their medication, many said it is a feeling they get inside of them and that they can never forget it. One participant explained that he can taste it in his mouth when his next dose of ART is due. Pill taking has been described as part of life. The participants are constantly aware of their schedule. This feeling they are referring to is a clear indication that the routines they have developed came naturally to them, incorporated the realities of their lives and assisted them in maximizing adherence. Participants made use of various mechanical devices that acted as physical reminders. Watches and cell phone alarms were most commonly utilised. One participant did not have either, but listened to the radio and could link the time of taking treatment with certain radio programmes. Other devices that are used as reminders include pill boxes and tick sheets. Two participants explained that they only used these aids when they initiated treatment, but stopped using it when they settled into a routine.

Patients are followed up on a monthly basis. At each visit, a pill count is done regardless of the length of time on ART. The adherence rate gets calculated. Overall, most of the participants commented that they did not mind it and find the positive feedback of a good adherence rate motivational and inspired them to maintain good adherence. One participant thought the pill count was a very good idea, as it provided him with feedback, informed him if he missed a dose and reinforced adherence.

The abuse of alcohol and other substances was also put forward as a reason for not being adherent (Kalichman et al, 2009). At least four participants (33%) mentioned that they had to reduce or stop their alcohol consumption. None of them stopped ART when they could not manage to do so.

Only one of the participants complained of experiencing side effects when taking ART. He did not stop treatment, but rather sought assistance from the clinic staff on how to manage the side effect. When asked about side effects, the participants focused on the positive effect of the ART rather than the negative and commented on how much stronger they felt and how much weight they have gained. When asked what they will do if they develop side effects now, they said they would seek support from the clinic staff and were adamant that it will not influence their adherence. Most patients did not seem to think that they can develop side effects after years on ART.

#### 4.6 Patient related factors

Several participants commented that they had to change their lifestyles or were planning to change certain aspects of it in the near future. Alcohol abuse and cigarette smoking were two common practices. The biggest challenge for them was to decrease or stop alcohol consumption and to stop smoking. One participant even decided to stop socialising with certain people whom he felt was a bad influence and did not support his goal of stopping drinking. Overall, the participants were striving to live a healthy life. Another participant was

an ardent soccer player before he fell ill. He had to give up soccer as he was not well enough to continue playing. He thought that he will never play again. The trust that he had put into ART and the positive effects he experienced from taking ART, gave him new hope and he is planning to start playing again soon.

All the participants displayed tremendous determination when they were asked if they would ever stop taking ART out of their own accord. They all answered with a resolute, no. One participant said that he can never stop his ART. The virus never lets go, and for that reason he can never get tired of taking his ART. Another participant commented that he can never stop the ART as it is his life. Despite low literacy levels, the participants had a good understanding of the different parameters that measures the progress of HIV, i.e. CD4 count and viral load. They also understood what HIV is and the role of ART in HIV. They were fully aware of the implications to their health if treatment was stopped. Research has shown that patients' understanding of their condition and treatment is positively related to levels of adherence (Sanjobo, 2008). Overall the participants chose life.

The participants displayed a great sense of responsibility. When they were asked directly who helped them to stay adherent, they all replied that it was their lives and they had to take responsibility for it. They clearly understood the fact that only they are responsible for their future wellbeing. This also contributed to the increased feeling of self-efficacy.

The perceived benefits of taking ART regularly was linked to the perceived negative consequences if they would stop ART. The participants also showed high levels of self-efficacy because they believed in the benefits of ART. The fear existed that they will fall ill again or die. This was also found in the Tanzanian study in 2009 by Watt and colleagues. When asked what advise they will give other patients starting ART, all the participants used themselves and their improved physical condition as a reason for taking ART and staying adherent. They viewed it as a personal achievement.

This desire to stay healthy and prolong their lives was not only an individual motivation, but also a social one. The participants with children and partners indicated that they wanted to stay healthy for their sakes as well. They wanted to be present to see the children go to school and support their partners. The uncertainty of what was going to happen to their family if they had to fall ill or die was too much to bear and the sense of obligation towards the family was a strategy that supported adherence.

# 5. **DISCUSSION**

There are many barriers to ART adherence. This includes poverty, stigma and discrimination and low rates of HIV disclosure (Mills et al, 2006). Despite these factors being present in the community that the participants come from, they managed to maintain a high level of adherence. Through semi-structured interviews, several factors were identified that facilitated adherence to ART. Similar to other studies (Watt, Maman, Earp, Eng, Setel, Golin & Jacobson, 2009; Gray, 2006), the belief that ART will be efficient to improve health and ensure a long life facilitates adherence. Participants based this belief on their own experiences of their health improving dramatically after starting ART. There are also other strategies like pill counts and providing the CD4 and viral load results that act as facilitators to good adherence. A positive result provides positive reinforcement and encourages and motivates participants (Starace, Massa, Amico & Fisher, 2006).

Patients did not take long to fall into a routine of pill-taking and incorporated this into their daily routines. They found a twice a day regimen to be manageable and easy and this facilitated adherence (Orrel et al, 2003).

In this study, participants trusted the clinic staff and found them to be a positive support system. They trusted the information and advice that the staff and doctor gave them. The influence that the provider-patient relationship has on adherence has been well documented (Schneider, 2004; Beach et al., 2006). The fact that the participants were followed up by the same team and built a relationship over time, could possibly contribute to the high levels of adherence. As the patient load increases, patients might not be seen by the same health care provider at each visit which might affect adherence. Home visits were conducted as recommended by the National Antiretroviral Treatment Guidelines pertaining to adherence. Home visits are a facilitator to adherence and should be an integral part of any antiretroviral programme. This approach is well suited in communities who need it and it was found that this strategy to improve adherence addresses individual behaviour and emphasizes individual actions to change the barriers to health (Williams, Fennie, Bova, Burgerss, Danvers & Dieckhaus, 2006). Interventions that have improved adherence in resource-limited settings include telephone calls and nursing home visits (Wang, 2010).

Viral load data should not be used as the sole parameter whereby adherence is measured. It should be accompanied by pill counts or other methods of ensuring 100% adherence. Further

studies are warranted with more specific inclusion criteria to eliminate the possibility of defaulters in the sample. One participant admitted that he stopped treatment twice before for a minimum of two weeks each time. Despite these bouts of non-adherence the participant still had an undetectable viral load. More reliable viral suppression with non-nucleoside reverse transcriptase inhibitors (NNRTIs) at modest levels of adherence may be the result of either an improved potency or the extended half-life of the NNRTIs (Bangsberg, 2006). He was working away from home and forgot to collect additional treatment from the clinic to take with him. Being away from home, ranked as a number one reason for missing doses (Nachega et al, 2004) which, although based on the low sample size, appears to be supported in this qualitative study.

The fact that treatment was free and clinic services too could be another facilitator to adherence. The proximity of the clinic (Mills et al, 2006) and the fact that he participants were free during the day to attend the clinic are facilitators to adherence. The majority of patients were unemployed, but Nachega and colleagues (2004) found that unemployment was associated with lower levels of adherence as many participants in that study would go away to look for work. The clinic staff at the clinic where the interviews were conducted played a big role in preparing the patients to deal with possible barriers to adherence. The patients were advised to approach the clinic staff when they were planning to go away to ensure that they take enough ART with them. The clinic staff had flexible schedules and realised the importance of not having a break in ART. They accommodated patients who missed their appointments and also encouraged them to send treatment buddies to collect treatment when they could not.

One of the two working participants that were interviewed came during his lunch break to collect his treatment. The other participant took the day off work to attend the clinic. This can become a problem as employers do not like employees to be absent from work too much. Having the ability to institute job accommodations were very important to adherence and was found to be a positive facilitator to adherence. The potential benefits of requesting modifications need to be weighed against the possible risks of workplace disclosure (Torres-Madriz, Lerner, Ruthazer, Rogers, & Wilson, 2010). Difficulties to coordinate work and adherence were identified as a barrier to adherence (Mills et al, 2006), but this was not a problem for the two participants who were employed.

Knowing someone on ART or living with someone on ART facilitated ART adherence. It mimics the scenario of being part of a support group. Participants found that they could talk about HIV and ART to their partners and they also reminded each other to be adherent. Watt et al. (2009) found that the participants found resonance in the information and support that was provided to them by clinic staff who was also HIV positive and who shared the same personal experiences. The National Antiretroviral Treatment Guidelines provide clear criteria on when to start ART and lists recommendations of processes that should be in place before ART is commenced. The clinic where the study was conducted was well resourced. There are 120 patients on ART and three lay counsellors. Each counsellor has a certain amount of patients assigned to them to follow up. With such small numbers it was still an easy task. It is a very labour intensive programme. In other clinics where there is a high patient load, it can pose a problem and place a high burden on the health care system. These clinics might not be so fortunate to have a big staff complement and will find it difficult to adhere to the guidelines which can be detrimental to the patients.

Feedback should be given to the patients during their routine adherence discussion with the lay counsellors or the staff member performing the pill counts. Overall, the participants found that feedback regarding their CD4 count and viral load very positive and encouraging. It was rewarding to see that their efforts to stay adherent was successful. Positive feedback regarding a pill count with an adherence rate of more than ninety five percent instilled a sense of pride and success in the participants which in turn fosters a need to maintain adherence.

This study provides more insight and understanding of why adherence might be higher in this setting despite the presence of possible barriers to adherence. The National Antiretroviral Treatment Guidelines acknowledges the fact that adherence to a complex ART regimen is a multidimensional process. It involves the health care provider and the patient acting as a team. The guidelines focus on preparing the patient on a psychosocial level, education and equipping the patient with adherence tools such as physical reminders. The clinic where the study was performed strictly adhered to the guidelines and achieved great results. Many studies have shown that it is impossible to predict which patients will be adherent. It is therefore better to concentrate on patient preparation rather than using non-clinical data (level of education, gender, etc.) as predictors of adherence (Coetzee et al, 2004). As the clinic grows, there is always the risk that the patient preparation time will need to be shortened to accommodate the increasing patient load. This will impact on adherence.

# 6. CONCLUSION

The clinic staff followed the recommendations of the National Antiretroviral Treatment Guidelines pertaining to adherence. It is of the utmost importance that clinic staff at ART clinics be familiar with these guidelines and receive proper training on how to implement these. Application of these guidelines can be a positive intervention contributing to the good virological response of the participants. Further studies must be undertaken to measure the effect of different adherence programmes on adherence rates.

High rates of adherence are required for ART to be effective. There is a need to recognise the unique nature of the strategies people employ to take ART. The participants in this study came from a very poor community where unemployment rates are high and people live in informal settlements. The fear existed of being stigmatised and discriminated against by the community. These circumstances are not conducive to maintaining adherence, yet they managed to stay adherent. The specific strategies and reminders they used were unique to each participant and the clinic staff must be fully aware of the fact that not all patients are the same. The participants used different electronic devices (cellphones, radios, alarms) that they already had in their possession, as reminders when they could not afford to buy new devices. Strategies were different for those who had partners who were also HIV positive and taking ART to those who did not have partners or disclosed their HIV status to family members and friends. The participants felt that their HIV positive partners had more insight into their problems, could provide them with information and reminded them when to take their medication. Each participant chose their own pill taking time. This gave them the freedom to incorporate pill taking in their daily schedule. This was especially true for the two who were employed. Each participant identified a different social support system according to how comfortable they felt towards them. Each participant dealt differently with issues surrounding stigmatisation depending on their circumstances. Such information is invaluable to the clinic staff. It is recommended that the clinic staff explore the different strategies on an individual patient level, taking cognisance of their individual circumstances. The experiences of other patients taking ART can be useful and can be incorporated in the initial treatment preparation sessions.

Good adherence resulted in improved laboratory results and markedly improved health. The benefits of adherence were obvious and further reinforced positive adherence behaviour. Patient adherence is a complex issue and requires the clinic staff to be very involved with adherence checking. Home visits and regular pill counts were strategies positively associated with adherence. The importance of home visits must not be underestimated, especially during the preparatory phase of a patient starting on ART. It is recommended that clinic staff set precise objectives for home visit achievements. One of the objectives should be to identify possible barriers to adherence. Regular pill counts are essential and it is recommended that clinic staff must be trained to do this properly and calculate adherence rates precisely. Pill counts are not effective as an adherence tool unless it involves feedback to the patient. A patient's circumstances can change which can affect adherence and therefore pill counts should be part of every visit, even if the patient has shown to be one hundred percent adherent in the past. If the number of patients increases beyond the capacity of the clinic, continuing to employ strategies to enhance patient adherence will be impractical. This can lead to a huge burden on the healthcare system. It is crucial to build partnerships with organisations in the community that deliver similar services. Non-governmental organisations (NGO's) that train lay counsellors or patient advocates can be a source of assistance in strengthening the community based support system. The Hospice can be incorporated in the referral system when a patient needs palliative care and support. The patients can be a source of assistance and can be trained to be patient advocates, assist with home visits or lead support groups.

The guidelines suggest investigating barriers to adherence only when there is suboptimal adherence. Information dissemination and acceptance of HIV status prior to starting ART improves adherence (Westerfelt, 2004). Identification of possible barriers to adherence must be done during the treatment preparation sessions and patients prepared on how to deal with any eventualities. The outcome of the study supports the National Antiretroviral Treatment Guidelines pertaining to adherence. It is necessary to reinforce these guidelines at every clinic that provide ART services. It is recommended that all the health care team members receive specific training regarding ART and adherence and should be updated periodically. Regular meetings with all the different role players are essential and should provide feedback on the progress of the different adherence support activities.

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