# Factors that affect adherence to antiretroviral therapy among adolescent patients at selected Palapye clinics

by

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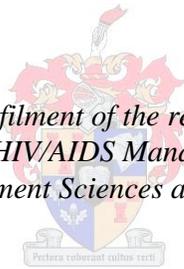
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March 2013

Declaration

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Abstract

This study, which was conducted from 1 to 31 October 2012, was aimed at describing the main factors that influence adolescent adherence to antiretroviral treatment in three selected health facilities of Palapye Health District. During the one-month data collection period, 30 adolescents were interviewed using semi-structured interview tools.

Different factors influencing adolescent adherence to antiretroviral treatment were highlighted and adherence to such treatment was measured using the method of calculating the percentage of returned pills. The mean adherence level for the entire sample was 76.96%, with common factors contributing to poor adherence among adolescents being found to be the poor processing of disclosure, stigma, the accessibility of health facilities, due distance and waiting time, the nature of social support, and feelings toward taking antiretroviral. Thus, by addressing adolescent adherence to antiretroviral treatment, adolescent-adherence counselling before and during treatment is to be shaped, insisting on the preparation of young patient caregivers for the process of disclosure; the reinforcement of positive messages during consultations; insistence on the importance of disclosing HIV status to others; the implementation of the antiretroviral dispensing outreach at health posts; and exerting effort to reduce the waiting time at health facilities prioritising young patients and adolescents.

Opsomming

Hierdie studie, wat vanaf 1 tot 31 Oktober 2012 onderneem is, het ten doel gehad om die hooffaktore te beskryf wat adolessente se getrouheid met antiretrovirale behandeling in drie gekose gesondheidsfasiliteite in die Palapye-gesondheidsdistrik beïnvloed. Semigestruktureerde onderhoude is gedurende die maand lange datainsamelingstydperk met 30 adolessente gevoer.

Die studie dui op verskillende faktore wat adolessente se getrouheid met antiretrovirale behandeling beïnvloed, welke getrouheid gemeet is aan die hand van die persentasie teruggestuurde pille. Die gemiddelde getrouheidsvlak vir die algehele steekproef was 76,96%. Algemene faktore wat oënskynlik tot swak behandelingsgetrouheid onder adolessente bydra, is die swak verwerking van MIV-statusonthulling, stigma, die toeganklikheid van gesondheidsfasiliteite, reisafstand en wagtyd, die aard van maatskaplike steun, en gevoelens oor die gebruik van antiretrovirale middels. Hierdie ondersoek na adolessente se getrouheid met antiretrovirale behandeling behoort adolessentberading oor behandelingsgetrouheid voor én gedurende behandeling te rig. Die klem moet in die besonder val op die voorbereiding van die versorgers van jong pasiënte om die onthullingsproses beter te hanteer; die versterking van positiewe boodskappe gedurende konsultasies; die belang van MIV-statusonthulling aan ander; die inwerkingstelling van uitreikaksies om voorskrifte vir antiretrovirale middels by sogenaamde 'gesondheidstasies' te resepteer, en daadwerklike pogings om die wagtyd by gesondheidsfasiliteite te verkort, met voorrang aan jong pasiënte en adolessente.

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1.   INTRODUCTION

1.1   Accessing antiretroviral therapy (ART)

According to the UNAIDS *Report on the Global Aids Epidemic* published in 2010, by the end of 2009 more than five million people were receiving antiretroviral therapy (ART) for the first time, which meant an increase of 30% in the number of people receiving treatment in a single year. Overall, the number of people receiving therapy has grown 13-fold since 2004, with more than five million people in low- and middle-income countries, consisting of 36% of the 15 million people in such countries who are in need of such treatment, receiving ART. Expanding access to treatment has contributed to a 19% decline in deaths among people living with HIV between 2004 and 2009 (UNAIDS, 2010, p. 95).

Botswana is still one of the countries that is most severely affected by the HIV epidemic, with a national prevalence rate of 17.6% in 2008 (*BAIS III*, 2008). The national prevalence among pregnant women between 15 and 49 years old who were attending government antenatal clinics was 31.8% in 2008.

Botswana was the first country in sub-Saharan Africa to launch a free national ART programme in the public health sector. Since then, the country has achieved among the world's highest coverage rates for HIV treatment, delivering antiretroviral (ARV) drugs in 2010 to more than 94.5% of those who needed the medication (UNAIDS, 2010, p. 98)

1.2   Lack of adherence to the ART regimen

Whereas highly active antiretroviral therapy (HAART) has significantly improved the lives of many HIV patients worldwide, the lack of adherence to the treatment remains a major challenge to HIV and acquired immune deficiency syndrome (AIDS) care, which is having serious public health consequences. The failure to adhere to HAART often leads to treatment failure and to the likelihood of accelerating the emergence of drug-resistant strains of HIV. As Botswana scales up access to ART in all its health facilities, there is a critical need to estimate

and to monitor the rates of adherence concerned. It is also important to understand the factors that influence adherence, in order to facilitate the design of appropriate interventions (Joyce et al., 2004, p. 9).

1.3   Focus of the current study

The current study was conducted in three clinics situated in Palapye District, in the Central region of Botswana. The clinics concerned, which are situated in the Maokatumo, Maunatlala and Lerala villages, provide ARV drugs on a weekly basis, apart from other primary health services.

More than two thousand HIV-positive patients, including a number of adolescents aged between 13 and 20 years, are currently receiving HAART within the three selected study sites. The reports of poor adherence to HAART among the HIV-positive patients aged between 13 and 20 years necessitated the current research.

1.4   Accessing HAART

HAART has been proven to be effective in suppressing HIV replication, in decreasing morbidity and mortality rates associated with HIV, and in improving the quality of life in adults, as well as in children, infected with HIV. However, many factors can affect the ability of HAART to suppress viral replication, including the low potency of one of the drugs in the combination, viral resistance, inadequate drug exposure, and inadequate adherence to therapy (Starace, Massa, Amico & Fisher, 2006, p. 154). Drugs do not work in patients who do not take them, and, in the management of HIV infection, it is now well established that optimum adherence to HAART is critical to the successful outcome of patients receiving therapy. At least 95% adherence to HAART is optimum, and studies have shown that <95% adherence is associated with a virologic failure rate of >50% (Shah, 2007, p. 55).

1.5   Growing concern regarding levels of adherence to the ART regimen

Although ART has been available through the public sector in Botswana since 2002, there is continuing concern regarding the level of adherence, especially among adolescents. Studies conducted in Botswana have reported adherence levels of 83% (Nwokike, 2004) in the public sector and 54% (Weiser et al., 2003) in the private sector, being rates that are below the minimum level of 95% that is required for treatment success and for the delaying of the emergence of drug-resistant strains.

To date, studies in Africa and in developed countries in other continents have mainly reported on adherence rates, with few of them being qualitative studies reporting on barriers to adherence in infants and adults. Therefore, qualitative studies are required to identify the barriers to, and facilitators of, adherence among adolescents on such continents and in such countries. Important factors that influence adherence to HAART, such as regimen-related complexities, patient-/family-related issues and factors that are related to the healthcare delivery system, make adherence to HAART challenging. Numerous interventions to improve adherence have been cited and investigated in studies conducted in both developed and developing countries, with one of the most important noted among them being counselling.

Many HIV management policies are focusing on the counselling that is required to improve the outcome of the ART undertaken. In Botswana, pre-treatment and on-going counselling is offered to all patients both before and during the treatment, but the reasons are not known why HIV-positive adolescents tend to adhere poorly to HAART, compared to how other age groups do.

1.6   Research regarding poor adherence to the HAART regimen

The research question for the current study was: 'What are the main factors that contribute to poor adherence to HAART among adolescent patients aged between 13 and 20 years old?' The identified factors will be used in recommendations aimed at enhancing adolescent HAART adherence levels, in order to improve the ARV programme's effectiveness.

Numerous research reports have been published regarding adherence to HAART among adults and children in many countries. However, limited information has been published about adherence to HAART among adolescent patients. The results of the current study could add to the existing body of knowledge regarding adolescent adherence to ART in sub-Saharan Africa in general, and particularly in Botswana. Policy-makers could consider the importance of the results of the present study for improving adolescent adherence to ART in Botswana. Health care providers working in facilities providing ART could utilise the results of the study to improve the quality of pre-treatment and on-going adherence counselling among adolescents.

Improvement in adhering to HAART would contribute significantly to a reduction in the transmission of the HIV infection horizontally among youth and vertically from mother to child.

A significant reduction in prevalence among youth of 15-24 years old has been observed in Botswana, and, because the group concerned is normally used as a proxy for new infection, it is believed that, by reinforcing the strength of adherence counselling, the level of adherence among adolescents should be enhanced. Such intervention would considerably influence the reduction in the number of new HIV infections. In 2009, HIV prevalence in the age group 15-19 years and 20-24 years was 13.2% and 24.1%, respectively, in comparison with the 24.7% and 38.7% prevalence in the same age groups, respectively, in 2001 (*BAIS III*, 2008, p. 13).

2.   LITERATURE REVIEW

2.1   Non-adherence to the ART regimen among adolescents

In the majority of low- and middle-income countries, HIV has become a chronic disease since the implementation of universal access to HAART. Successful ART results in the suppression of HIV replication, and halts the clinical progression of the disease. A clear, positive relationship between ARV adherence and the achieving and maintaining of virological suppression has been established. Non-adherence to ART, evidenced as missed doses, is associated with incomplete viral suppression, and with the development of a drug-resistant virus, which, eventually, is bound to limit therapeutic options (Machtinger et al., 2006, p. 514).

Adherence is defined as "the extent to which a patient's behaviour coincides with the prescribed healthcare regimen, as agreed upon through a shared decision-making process between the patient and the health care provider" (KITSO AIDS Training Program, 2010). Very high (greater than 95%) levels of adherence are required for ARV drugs to be effective and to prevent the emergence of resistant viral strains. Such high levels of adherence require missing out on no more than three doses a month for a twice-daily regime, and maintaining said level of adherence year after year (Zuurmond, 2008, p. 5)

An adolescent is defined by the World Health Organisation (WHO) as a person who is between 10-19 years of age. About 1.2 billion adolescents exist worldwide, with one in every five people in the world being an adolescent (WHO. Regional Office for South-East Asia, 2012). The Botswana Ministry of Health's definition of an adolescent as a person who is aged between 13 and 20 years old is used in the current study (Botswana. Ministry of Health, 2008, p. 30).

2.2   The importance of obtaining optimal levels of adherence to the ART regimen

A dramatic reduction in HIV-related morbidity and mortality rates has been recognised in countries where HAART has been made widely available (Anna et al., 2002). However, it is also recognised that extremely high levels of adherence to ART (at least 95%) are needed to ensure optimal benefits, and that maintaining such high levels may often be complex, in terms of the pill burden, the dietary restriction, and the dosing frequency involved. Where adherence to said regime is suboptimal, HIV rapidly selects for resistance, in part due to rapid and error-prone replication (Joyce et al., 2004, p. 17).

It has been estimated that one-quarter (25%) of ART users in Africa do not achieve optimal adherence. Of even greater concern is the fact that a more recent systematic review of African ART treatment programmes calculated that up to 40% of all patients receiving ARVs are thought to have died or discontinued treatment within two years of starting on ARVs (Zuurmond, 2008, p. 6)

The goal and benefit of HAART may be defined both clinically and biologically. Clinically, HAART prolongs life and improves the quality of life of those living with HIV, by reducing, as much as possible, the frequency of the HIV-related illness that is known as AIDS. By reducing the mortality rate due to AIDS, ARV drugs also have the controversial effect of increasing the number of people living with HIV, because they tend to live much longer than they would do without the treatment. Biologically, HAART is responsible for the immune reconstitution that is both quantitative (referring to the CD4 cell count in normal range) and qualitative (referring to the pathogen-specific immune response). HAART also causes the greatest possible reduction in viral load (preferably to less than 50 c/mL) for as long as possible, in order to halt disease progression and to prevent or to delay progression (Bartlett, Gallant & Conradie, 2008, p. 38).

Adherence to treatment is critical to obtain the full benefits possible from HAART. The maximal and durable suppression of viral replication reduces the destruction of CD4 cells,

helps to prevent viral resistance, promotes immune reconstitution, and slows down the progression of disease.

The relationship between adherence to the ARV regime and the development of resistance is not linear. Patients with low adherence levels do not exert sufficient selection pressure to confer a replication advantage for drug-resistant mutants. Patients with high adherence levels suppress replication, and mutations do not occur. Resistance is opted for by patients with moderate adherence. While all ARV drugs are susceptible to resistance, the degree of susceptibility varies. A single viral mutation results in complete resistance to the non-nucleoside reverse transcriptase inhibitors (NNRTIs), namely efavirenz and nevirapine. Similarly, lamivudine is rendered ineffective by a single mutation. In contrast, other nucleoside reverse transcriptase inhibitors (NRTIs) and the protease inhibitors (PIs) are more robust, requiring multiple viral mutations before resistance develops.

Because a resistant virus is only generated if there is adequate drug pressure to drive the development of the mutations involved, different ARV classes are vulnerable at different adherence rates. Resistance to a PI is noted most frequently when adherence is between 80% and 95%, as high levels of drug are needed to create enough selective pressure to confer survival benefit on a virus with multiple mutations. Lower levels of drug do not create enough pressure, so that a wild-type virus will remain the dominant virus.

Conversely, resistance to NNRTIs is more likely at <80% than at 80-95% adherence. The single mutation that confers resistance to an NNRTI does not impact on the virus's ability to replicate. Higher drug levels suppress the virus, and do not allow generation of the mutation concerned. Lower levels of NNRTIs secondary to <80% adherence commonly cause resistance (Wilson, Cotton, Bekker, Meyers, Venter & Maartens, 2008, p. 515).

Despite the above-mentioned complexities, the message to an individual on ART remains the same. Long-term viral suppression will only be achieved with near-perfect adherence (>95%).

Figure 1 below indicates virological failure rates in percentages and adherence to ART.
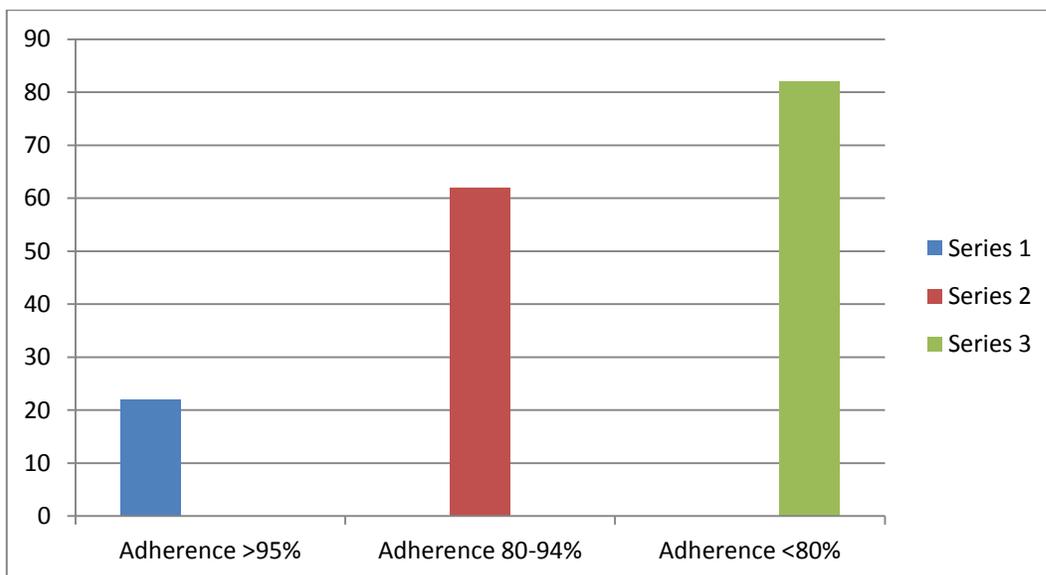
Figure 1.   **Virological failure rates (%) and adherence to ART**

(Paterson, Swindells, Mohr, Brester, Vergis, Squier, Wagener & Singh, 2000)

Paterson et al. (2000) found that adherence greater than 95% is needed to achieve virologic success, especially for PI-containing regimens.

As the levels of adherence decreased, the viral loads increased sharply, in a dose–response effect. The study showed that 22% of patients with adherence of greater than 95%, 61% of patients with adherence between 80-94.9%, and 80% of patients with adherence levels of less than 80% demonstrated virological failure. Such failure was regarded as indicating the presence of detectable viral loads (Paterson et al., 2000).

In countries with broad access to effective ART, the clinical benefits have been dramatic. Far fewer are progressing into becoming people with AIDS, hospital AIDS wards have practically emptied, and the age-adjusted death rate from HIV/AIDS has declined by more than 70%. Adherence to ART has emerged as both the major determinant and the Achilles' heel of said success.

The lack of ARV adherence is the second strongest predictor of progression to AIDS and death, after the CD4 count. Incomplete adherence to ART, however, is common in all groups of treated individuals. The average rate of adherence to ART is approximately 70%, despite the fact that long-term viral suppression requires near-perfect adherence. The resulting virologic failure diminishes the potential for long-term clinical success. Drug-resistant strains of HIV selected through ongoing replication in the presence of ART can also be transmitted to uninfected or drug-naive patients, leaving them with fewer treatment options. Non-adherence may eventually undermine the dramatic improvements in HIV-related health parameters seen in resource-rich countries, and expected in developing countries, as ART becomes more widely available. Adherence is not the only determinant of ART failure or success. Other factors include genetic differences in drug metabolism, severe baseline immune suppression, and prior drug resistance (Machtinger & Bangsberg, 2006).

Whereas strict adherence to ART promotes viral suppression, poor adherence results in further immunosuppression and in resistance to ARV medications (Chakraborty et al., 2008, p. 458). If there is poor adherence, then there is a higher risk that drug resistance will develop, which will result in the need for the second-line drug regimen. Said regimen can be more difficult to administer than the first-line treatment, with the cost implications of such treatment being considerable for the already low-income countries, as the second-line drug regimen costs almost ten times more than does the first-line drug regimen. As a result, the long-term implications for the sustainability of ART in resource-poor countries are considerable, as WHO states. Drug resistance may result in the failure of the extensive global and national efforts to provide hope to people living with HIV (Zuurmond, 2008, p. 5).

2.3   The importance of obtaining maximum compliance from adolescents in adhering to the ART regimen

Adolescents who are infected with HIV also face challenges in adherence. Several studies have identified the 'burden' that is placed on them to continue with the medications, which restricts their lifestyle options, leading to a situation that discourages them from wanting to keep their medications with them.

The denial and fear of HIV infection, which is especially common among the newly diagnosed young, might lead to a refusal to initiate, or to continue with, ARV therapy. Mistrust of medical treatment, misinformation about HIV, lack of knowledge about the medications, and the lack of availability and efficacy of ART can all act as barriers to adherence among adolescents, due to their concern and lack of conviction about their treatment, leading to them not properly monitoring their abiding by their ARV therapy regimen (Xochihua-Diaz, 2009)

Adolescents commonly experience such challenges as the taking of complex medication regimens and the following of a continuous medical care routine. However, adolescents might have long histories of poor adherence. Regardless of the mode of acquisition of the HIV infection, infected adolescents might have very low self-esteem, leading to depression, chaotic lifestyles, and drug addictions, together with mental illness and poor adaptation to the social environment of their disease, due to a lack of family and social support. Depression, alcohol or drug abuse, school truancy, and the experiencing of advanced HIV disease are correlated with non-adherence (Murphy, Belzer, Durako, Sarr, Wilson & Muenz, 2005).

In Europe, it has been reported that Italian children who received ART from foster parents were more adherent than were those receiving drugs from their biological parents or other relatives. (Giacomet, Albano, Starace, De Franciscis, Giaquinto, Gattinara, Bruzzese, Gabiano, Galli, Vigano, Caselli & Guarino, 2003, p. 1398). Thus, it has been suggested that efforts to improve children's adherence to complex regimens should address the developmental, psychosocial and family factors that are significantly associated with non-adherence (Mellins, Brackis-Cott, Dolezal & Abrams, 2004, p. 1035)

Numerous studies conducted in Africa have reported that the medical providers involved tend to believe that poverty and stigma are common barriers to ART adherence in poorly resourced countries (Brackis-Cott, Mellius, Abrams, Reval & Dolezal, 2003, p. 252). Families are known to struggle with poverty, mental health and substance abuse problems, and disclosure issues, especially when the adolescents concerned reach the age of knowledge and discernment. In Senegal, the provision of free ARV has been reported to have a positive impact on ART

adherence levels (Laniece, Ciss, Desclaux, Diop, Mbodj, Ndiaye, Sylla, Delaporte & Ndoye, 2003, p. S103). A similar study conducted in Blantyre, Malawi, noted that the provision of free ARVs improved the stipulated programme's quality, and reduced the number of ART defaulters (Van Oosterhout, Kumwenda, Hartung, Mhango & Zijlstra, 2007, p. 1241). Rosen, Ketlhapile, Sanne and Desilva (2007, p. 524) state that the non-drug costs of obtaining treatment, including transport costs and the loss of income, might limit access even to free ARVs.

In Botswana, HIV-infected adolescents have special psychosocial issues that often lead to the following adherence problems: the denial of, and fear related to, HIV diagnosis; misunderstanding related to diagnosis and health needs; lack of belief in the efficacy of ARVs; the distrust of family practitioners and the healthcare system; low self-esteem and an unstructured, chaotic lifestyle; and limited familial and social support (Botswana. Ministry of Health, 2012, p. 80).

The data suggest that adolescents might be less likely than younger children to maintain effective responses to ART, which is generally related to problems with non-adherence to ART and psychosocial concerns, particularly depression. Hence, the most critical aspect of providing appropriate care to HIV-infected adolescents is the close monitoring of their psychosocial health, although the health professionals providing ARVs to young patients are often unaware of such complexities. Few training initiatives are designed to ensure that healthcare providers understand the psychosocial and logistic challenges involved with having to take ARVs on a daily basis. Such an understanding of common barriers is of potential benefit to the effective discussion of adherence strategies with patients and their caretakers (Phelps, Hathcock, Werdenberg & Schutze, 2010, p. 1).

2.4   Recommendations regarding the involvement of others in assisting with the ART compliance of adolescents

All ART clinics should identify staff with an interest in adolescent care that could be used to help ensure continuity of care to HIV-infected adolescents. The designated staff members could

form a 'therapeutic alliance' with adolescents, aimed at helping them to handle challenges to their well-being. Such 'continuity-of-care' providers should explore with the adolescents in their care issues of sexuality, safe sex, substance abuse, barriers to adherence, and community support. Although adolescents are often knowledgeable regarding their own health care, and are capable of attending medical appointments alone, as well as of taking medications independently, responsible adults should still remain involved in their care. To ensure continuous adherence to medications, an adult adherence partner should directly observe ingestion of all doses, even when the adolescent has a history of good adherence.

Peer support is also an important aspect of adolescent care. Due to the stigma that is involved, it is often difficult for adolescents to disclose their HIV status to their peers without fear of rejection. Clinics that have several HIV-positive teenagers should form peer support networks, such as teen clubs, at which the HIV-positive teens can meet and support one another. Such teen clubs, which were pioneered in Botswana, have been internationally recognised as forming an important part of key interventions for HIV-infected adolescents. (Botswana. Ministry of Health, 2012, p. 80).

2.5   Measurement of adherence to the ART regimen

There are no gold standards by which to measure adherence to medication. Many studies employ a number of methods, either alone or in combination, to measure the amount of adherence shown. The most common include: electronic drug monitoring (EDM) devices; pill counts; biochemical markers; pharmacy refill records; and various self-reporting tools, such as questionnaires and visual analogues. According to Gill et al. (2005), the hierarchy of adherence measures ranks physician and self-assessment reports the least accurate, the pill count intermediate, and the EDM the most accurate adherence marker. However, no single measure is appropriate for all settings or outcomes. The use of more than one measure of adherence has been found to allow for the strength of one method to compensate for the weakness of the other, and for the more accurate capturing of the information required to determine adherence levels (Vitolins, Rand, Rapp, Ribisi & Sevick, 2000).

2.5.1. Objective assessment

Objective adherence measures include pill counts, which entail patients bringing their remaining pills back in their respective containers during all refill visits, with the pharmacy technician counting all returned medication in order to estimate the number of doses that have been taken. Said method is the most frequently used to calculate the percentage of adherence practised. Unfortunately, the method can be time-consuming in a busy facility, and, in the long term, patients who know the system well will discard their tablets in order to meet the expected 100% adherence rate, although doing so is not common. In order to counter the patients making such a move, some pharmacists advise doing surprise or unannounced pill counts at the patients' home when said practice is suspected.

Another objective adherence measure employs pharmacy refill data, which has been shown to be capable of predicting virological failure and survival rates in Zambia and South African cohorts (Wilson et al., 2006, p. 516). The measure involved is the simplest method of objectively recording adherence, and is best suited to monitoring adherence in large ARV programmes. The number of times that a patient receives medication over a fixed period, such as a calendar year, is expressed as a percentage of the number of times that they should have collected medication, for example a patient collecting medication 11 times out of an expected 12 times in the previous year means that they have practised 92% compliance with the regimen.

Electronic monitoring, which is an adherence measure that entails using electronic devices fixed on the medication container cover that record each time that a bottle is opened, is only used in a research environment, due to the expense involved, and the need for computer and specific software to download the registered information on the return of the bottle. The method, however, is accepted as being one of the most accurate measures that is currently available.

Therapeutic drug monitoring entails the measuring of the plasma concentration of the ARV drug. Due to its invasive nature, it is impractical for use as the only assessment measure of

adherence. However, the method can be used in research on failing patients, in order to measure the concentration and the absorption of ARV drugs.

2.5.2. Subjective assessment

Subjective adherence methods are notoriously insensitive, although improvement in results can be obtained by adopting non-judgemental attitudes and by gaining the patient's trust (Wilson et al., 2008, p. 516). Subjective assessments include using recall questionnaires, which requires the pharmacy technician to ask the patient to recall doses missed over the preceding three days, with the percentage of adherence being calculated on the basis of the answer provided by the patient concerned. The method is the most widely used tool for collecting adherence data, but it can also be seen as weak, because it is based on the credibility of the patient involved.

A 30-day visual analogue scale (VAS) of doses taken might be regarded as a faster and more efficient means of obtaining similar information to that which can be obtained using the recall questionnaire.

However, all measures of adherence remain approximations, although they can be used to target individuals who require more intensive adherence interventions.

2.6   Risk factors for poor adherence to the ART regimen among adolescents

Factors that might have either a positive or a negative impact on an adolescent's pill-taking behaviour may be divided into three categories: patient-related; regimen-related; and disease-related. With the simple regimens that are available as first-line therapy, the major impact on adherence occurs at the level of the interaction of individuals on therapy with their families, communities and health carers. Caregivers have an important role to play in the adherence of children and adolescents to the ARV regimen, with the rate of adherence seeming to differ, depending on the relationship between the patient and their caregivers. The more favourable the relationships are, the more likely an adolescent is to remain adherent to the regimen over time. More attention than is bestowed on it at present needs to be given regarding the time of

disclosure of their HIV status to adolescents. The value of an HIV-positive adolescent being properly prepared for the disclosure, so that they might come to accept the fact that they have been infected should not be underestimated in terms of the future adherence quality.

2.7   Interventions aimed at improving adherence

2.7.1. Pre-treatment interventions

Individuals who start treatment should be well-prepared to do so. A standard information module should be presented to all patients, in order to ensure that they have a basic understanding of HIV and ART, prior to them starting a course of ARVs. Such instruction should also be offered to the carers of children and of adults with mental illness. A 'treatment buddy', identified by the patient where possible, should also be educated about HIV and ART.

The above-mentioned information can be given by the peer educator or the counsellor over multiple group or individual sessions, during the week or two weeks prior to the initiation of ART, with said session of education being followed up on by simple questions that are set to check that the patient has understood what they have been told regarding their illness and the treatment thereof.

2.7.2. Interventions during treatment

The majority of 'treatment-ready' people who start therapy are adherent to the regimen, and might be expected to have a suppressed viral load within 6 month after the beginning of the treatment. However, such is not always the case, as some patients do not manage to take their prescribed medicine correctly, and others tire over time, and begin to miss out on doses, due to pill fatigue. Patients who are poor adherers need to be identified as soon as possible, and to be targeted to receive more intensive adherence counselling that is tailored to covering issues that might lead to non-adherence. Discussions with patients on the ways to resolve such issues, the repetition of initial adherence counselling, the use of pillboxes, and home visits by an adherence counsellor to assess domestic circumstances are required.

3.   RESEARCH METHODOLOGY

3.1   Research methods of enquiry utilised

In the current study both quantitative and qualitative research methods of enquiry were utilised, targeting HIV-positive patients aged between 13 and 20 years who were registered at the identified study sites.

Adherence rates were measured using two methods. The first method entailed using patient self-reporting or two-day recall, with the patient concerned being asked to recall the frequency and timing of taking medication (i.e. ARVs), as well as their food intake, over the two days prior to the date of the data collection. The second method consisted of a one-month pharmacy pill count that was calculated by subtracting the number of pills returned by a patient from the number of pills that had been issued to them at the start of the month. The amount remaining indicated how much medication had been used by the patient during said period. The amount used was then divided by the expected amount, multiplied by 100, to determine the percentage adherence per participant over the month in question.

Information on how factors contributing to poor adherence were collected using semi-structured interviews with adolescent patients on HAART.

3.2   Sampling method and sample size

Adolescents struggling with adherence were referred by the consulting clinician to the researcher for the study. At the time of the current study, approximately 2 518 HIV-positive patients were receiving ARV within the three selected facilities; a convenience sampling method was used to enrol 30 patients aged between 13-20 years who have been on ARV for a minimum period of one years. Every third patient attending a scheduled clinic visit was referred by the clinician to the researcher assisted by a local health care worker for the interview. These patients were asked to participate in a voluntary interview with the

researcher. Consent was obtained from these participants for ethical purposes, after the aims of the study were explained to them and that non-participation would not affect future treatment.

3.3 Inclusion criteria

The adolescent patients on HAART for a minimum of one year, as administered by the Maokatumo, Maunatlala or Lerala clinic, who demonstrated that they were willing to take part in the study were included in the population of the study. Consent was obtained directly from adolescents aged 18 years and over, and, for those aged between 13 and 17 years old, consent was requested from both the adolescents and the caregivers concerned.

3.4 Data collection tool

Data were collected using anonymous interviewing, developed on the basis of the literature review. The questionnaire, which was administered by the interviewer, included 28 closed- and open-ended questions to assess the knowledge possessed about HIV and what factors contributed to poor adherence among the participants.

3.5 Data analysis and validation

The qualitative method of data collection used in the current research study was the phenomenological method, which involved describing the experiences of groups of individuals. As described by Christensen, phenomenological research involves "getting inside of people's heads" to see how they experience things (Christensen, Burke Johnson & Turner, 2011, p. 368). The collected data were analysed by searching for significant statements that had particular relevance to poor adherence to HAART. The statements concerned were recorded verbatim, or close as possible to the participants' own wording (Christensen et al., p. 369). Formulated 'meaning' statements were organised into clusters or themes. Finally, a summary description of the essence or phenomenological structure of the phenomenon under consideration was produced by integrating the statements, their meaning, and the clusters that they formed. The internal validity method used was data triangulation, which is described by

Christensen as the use of multiple data sources. An effort was made to interview different adolescents in a range of age groups who attended three different clinics situated in various villages. Limitation to a single data source from which to draw accurate conclusions was, accordingly, avoided (Christensen et al., p. 367)

The quantitative data were analysed, using Excel spread sheets. The data concerned underwent familiarisation, the development of a thematic framework, coding, charting and interpretation. The following variables were analysed: age; gender; the education level; the age of disclosure; the mode of disclosure; the length of time spent being aware of own HIV status; the feelings experienced regarding the taking of ARVs; the disclosure of HIV status to others (in terms of the amount of stigma involved); the support system; the side-effects of medication; own knowledge of HIV and ARVs; and distance from the health facility concerned.

3.6   Ethical considerations and issues of confidentiality

Permission to collect data was requested from the Ethics and Research Committee of the Ministry of Health of Botswana, from Stellenbosch University, and from the Palapye District Health Management Team. Compliance with ethical standards was achieved because all patients who participated in the study did so both anonymously and freely. No report indicated any specific patient's contribution, meaning that such contribution was not specified according to the facility involved. All data were kept stored electronically and safely secured, with access thereto only being granted on the provision of a set personal password. The data concerned were deleted at the end of the study. In addition, each participant was requested to sign a voluntary consent form, stating that they agreed to participate in the study.

4.   RESULTS

4.1   Demographics of the respondents

4.1.1. Age and gender

The age and gender of participants are given in given in Table 1 below.

Table 1

Age by gender

Gender	13 years	14 years	15 years	16 years	17 years	18 years	19 years	20 years	Total
Male	2	2	3	2	0	2	1	1	13 (43.3%)
Female	4	3	2	3	2	0	0	3	17 (56.6%)
Total	6 (20%)	5 (16.6%)	5 (16.6%)	5 (16.6%)	2 (6.6%)	2 (6.6%)	1 (3.3%)	4 (13.3%)	30 (100%)

More female participants took part in the study than did male participants. In percentage terms, 43.3% of participants were male and 56.6% were female. Adolescents of all relevant years were represented in the study. The mean age of participants was 15.7 years. The mean age for male participants was 15.8 years, whereas that for female participants was 15.6. The mean percentage of adherence for male participants was 72.2%, compared to 80.4% for female participants.

Figure 2 below describes the percentage of adherence according to the age of the participants involved in the study.
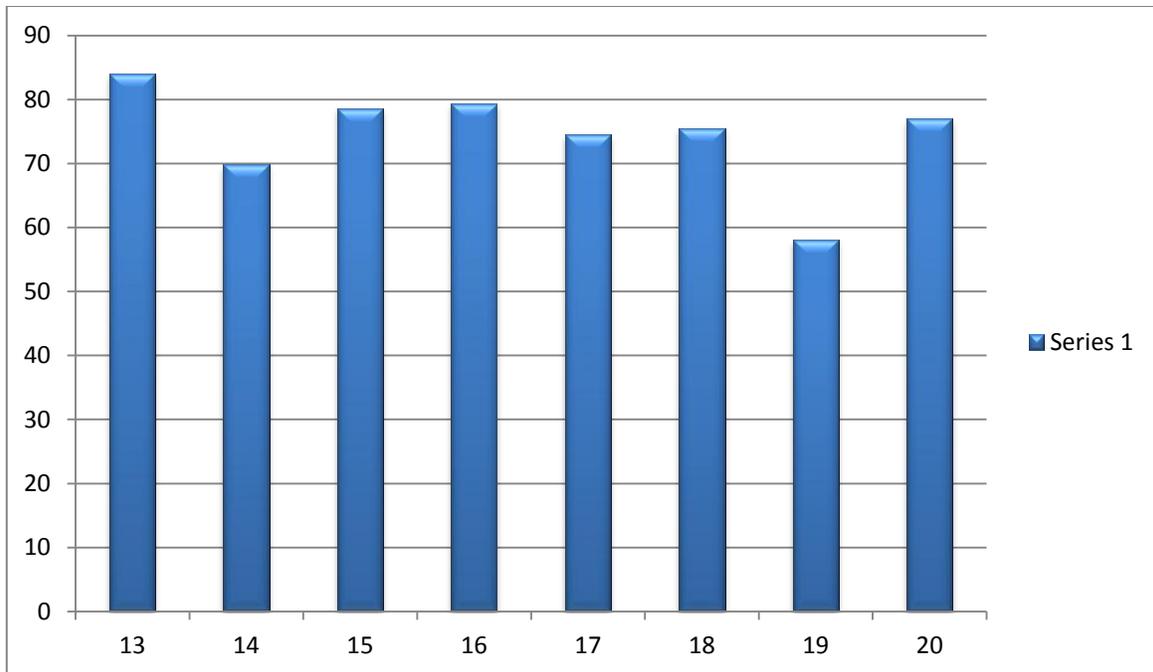
Figure 2.   **Percentage of adherence mean by age**

Level of adherence to ART among adolescents appeared to be higher in early teenage years and tended to decrease as the adolescents grew older.

4.1.2. Education level

Almost all of the participants were attending school at the time of data collection, except for two (representing 6.7% of the sample), who stated that they had never attended school. The majority of participants were attending secondary junior school. None of them were studying at tertiary level. Figure 3 below indicates the education level of the participants.
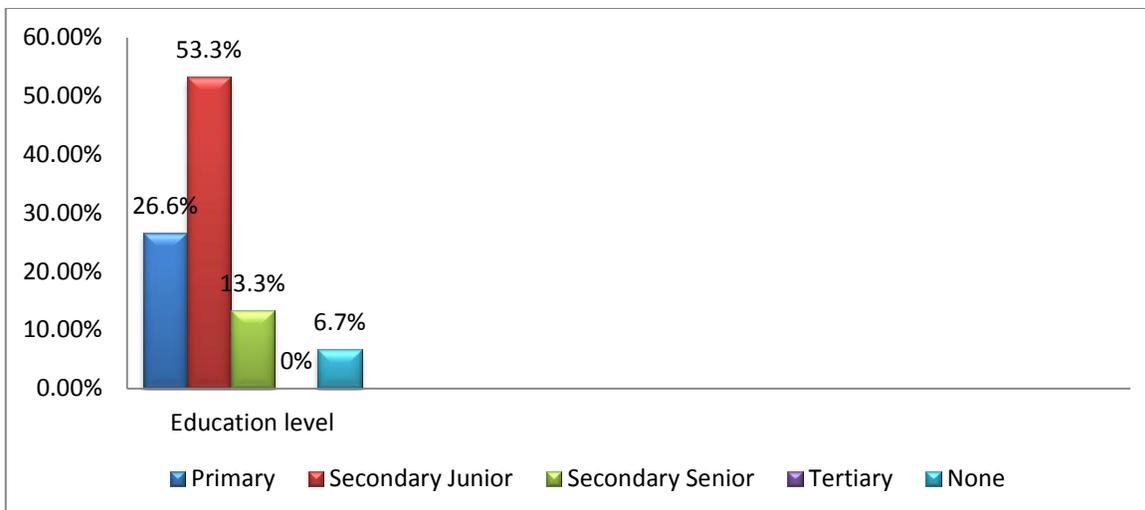
Figure 3.   **Education level**

4.2   Results pertaining to the adherence of the participants to the ART regimen

4.2.1. Percentage of adherence to the regimen

Figure 4 below indicates the percentage of adherence to the ART regimen.
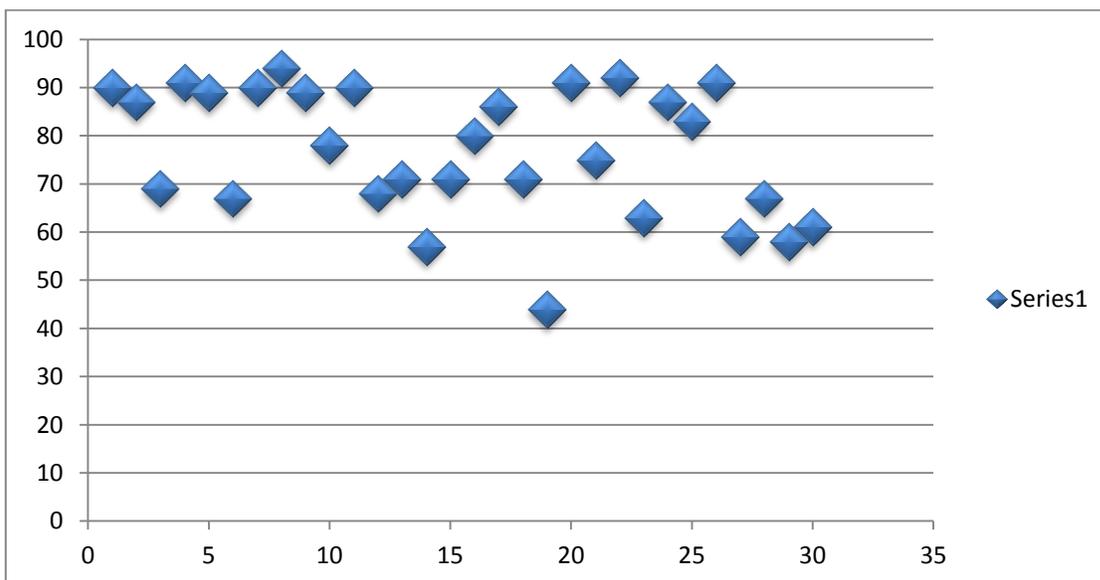
Figure 4.   **Percentage of adherence to ART**

The lowest adherence percentage was 44%, whereas the highest was 94%, with the adherence mean for the entire population being 76.9%, which was lower than the required adherence rate of 95% necessary to ensure the success of the ART. The percentage of adherence mean for male participants was lower (72.4 %) than it was for female participants (80.5 %).

Figure 5 below describes the percentage of adherence according to the education level, revealing that the lowest rate of adherence to ART was observed among the adolescents attending senior secondary school. The level of education was, therefore, found not to influence the level of adherence among the adolescents studied.
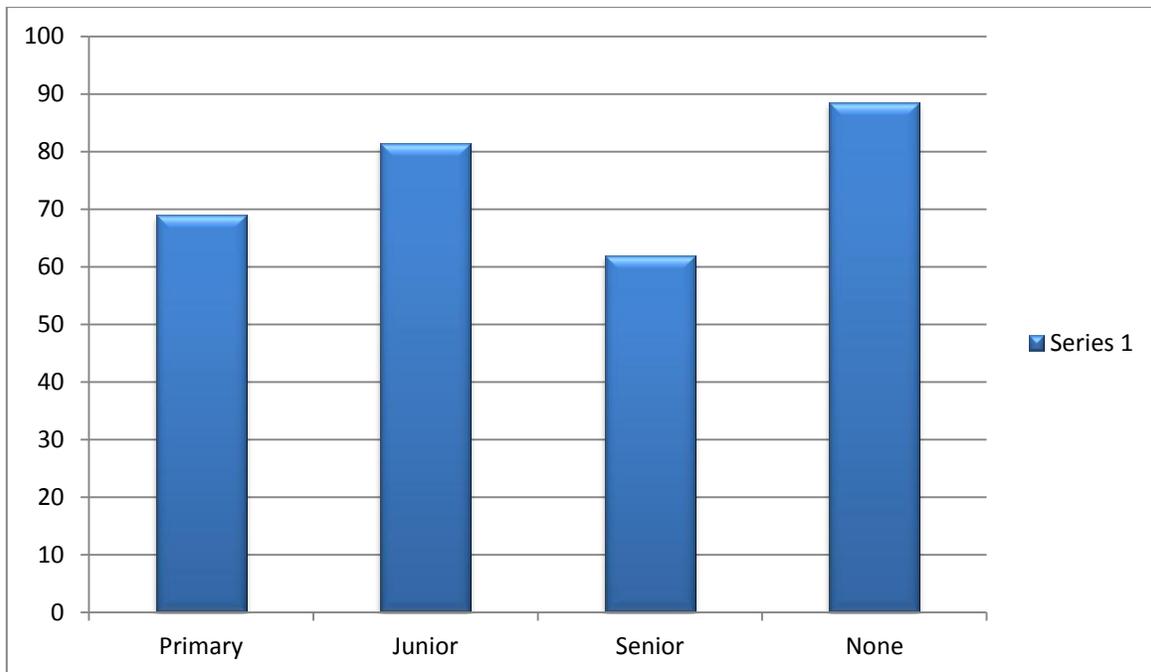
Figure 5. **Percentage of adherence mean by education level**

4.2.2. Length of time of awareness regarding own HIV status

Figure 6 below indicates the length of time of knowledge regarding own HIV status.
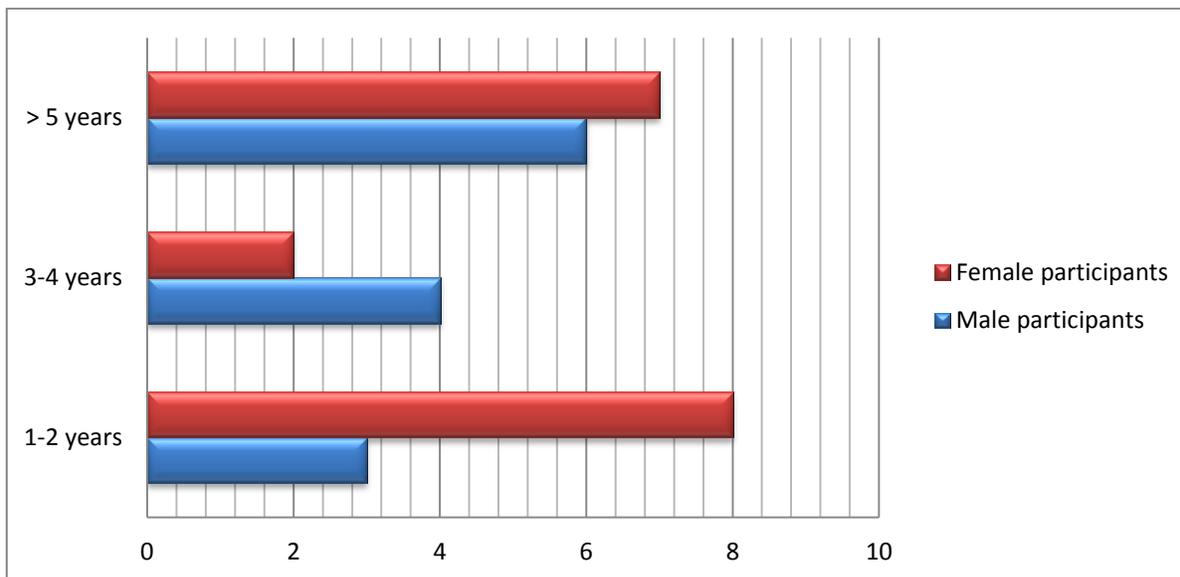
Figure 6. **Length of time of knowledge regarding own HIV-positive status**

The length of time of awareness of own HIV status varied amongst participants from 15 months to seven years. The above figure shows that most of the male participants had been aware of their own HIV status for more than five years, but the majority of female participants had only been aware of their own HIV status from one to two years.

Figure 7 below describes the variation of the percentage of adherence according to the length of time of awareness of participants' own HIV status. The lowest level of adherence to ART was clearly observed as being during the first year after the disclosure of the HIV status of the adolescents to them, with the level tending to increase after three and four years, and tending to decrease again after five years.
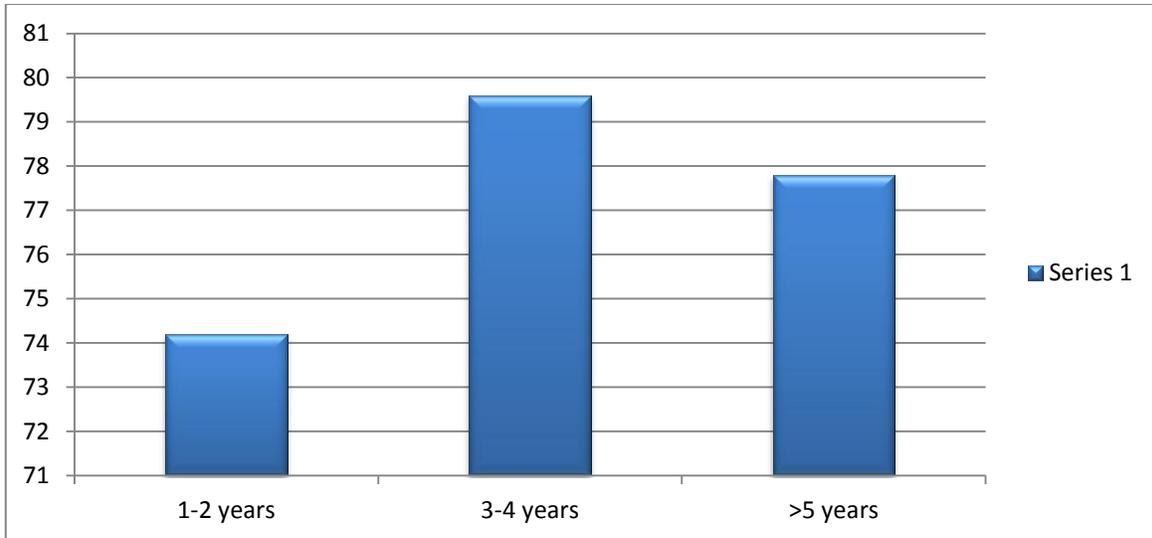
Figure 7. **Percentage of adherence mean by length of time of awareness of own HIV-positive status**

4.2.3. Age of disclosure of HIV-positive status to patients

The age of disclosure to patients was estimated by using the above-mentioned length of time of awareness of their own HIV status, together with the age of the participants. The mean age of disclosure was 12.3 years. Figure 8 below indicates the age of disclosure.
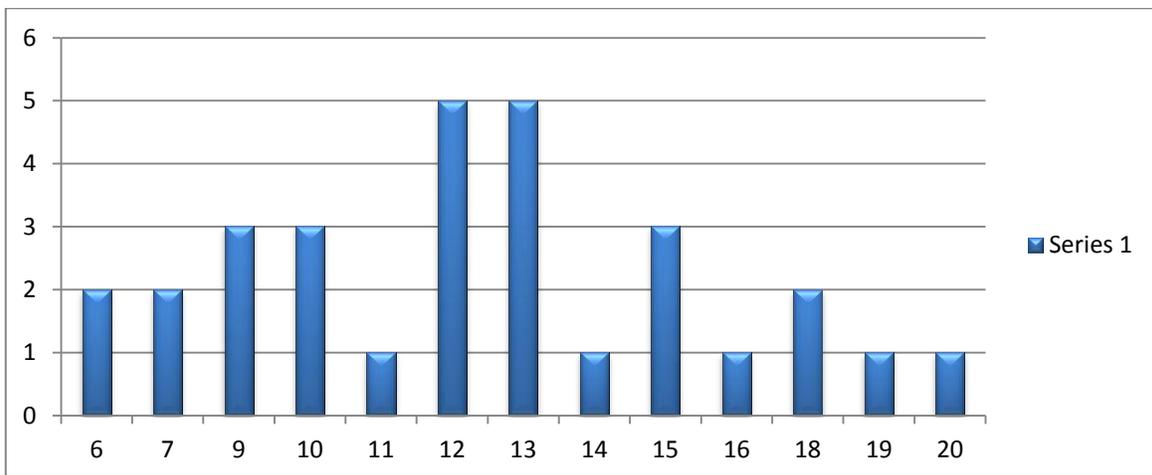
Figure 8. **Age of HIV-positive status disclosure to patients**

Figure 9 below describes the variation in the percentage of adherence, according to the age of disclosure. Adherence to ART seemed to have stabilised at an acceptable level when the disclosure process was undertaken when the patient was between the age of nine and eleven, but adherence was seen to be negatively affected when the disclosure process was performed at a later age.
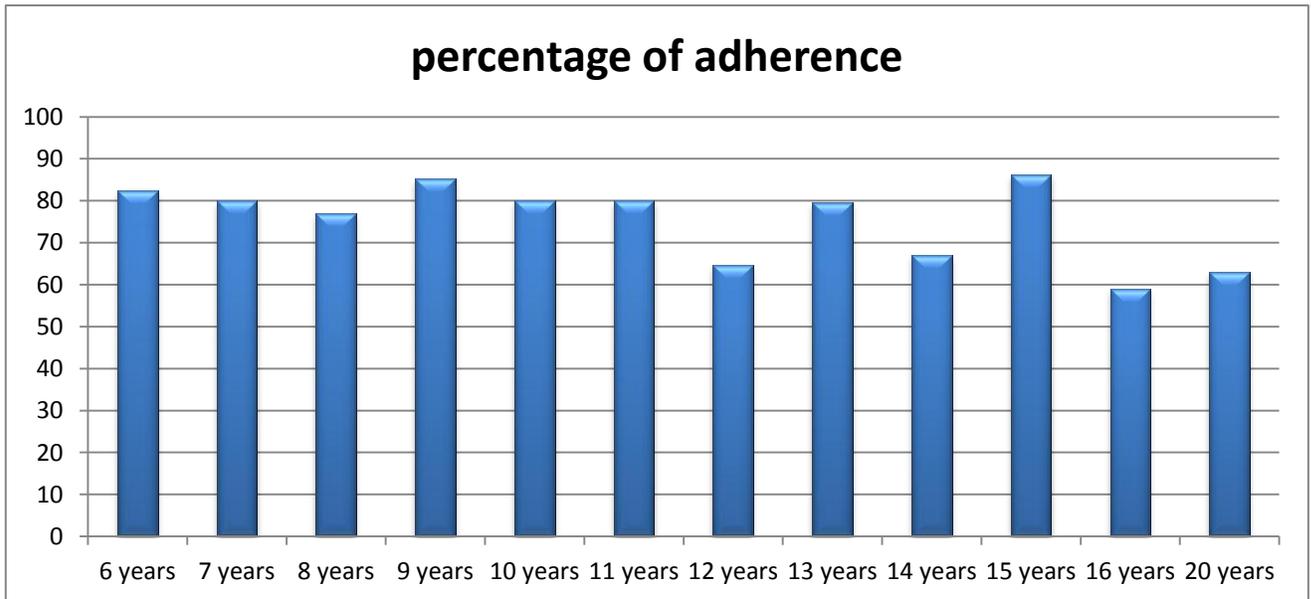
Figure 9. **Percentage of adherence mean by age at which disclosure occurred**

4.2.4. Mode of disclosure

Figure 10 below indicates the mode of disclosure.
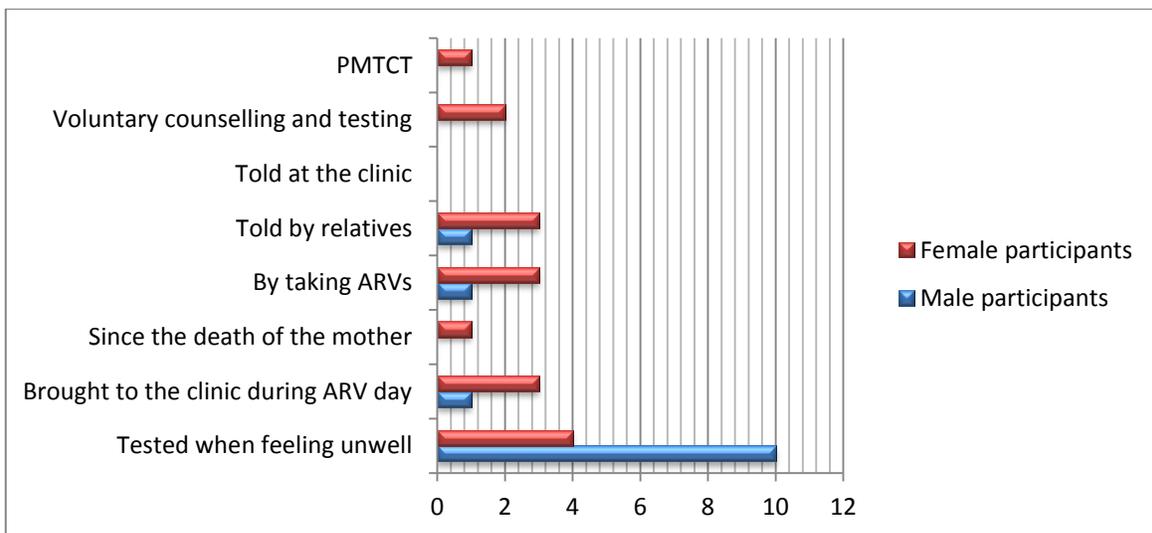
Figure 10. **Mode of disclosure**

PMTCT = prevention of mother-to-child transmission

The majority of participants stated that they had become aware of their own HIV status when they presented themselves for testing when they did not feel well, or indirectly, when they were brought to the clinic on the ARV scheduled day, or when they were prescribed ARVs. Only four of them (13.3%) had been told by their relatives, and none of the participants were told about their HIV status at the clinic by a health care provider.

Some of the participants' statements related to the mode of disclosure are listed as follow:
No one told me about my HIV status, but I realised it myself, because I was always brought to the clinic on Thursday, which is an ARV-scheduled day at Maunatlala Clinic.

One participant stated: "I knew [i.e. learned] about my HIV status only after the death of my mother, because I hear[d] people saying that she died because of HIV." Another participant said: "I was not told by my parents, but when I knew what the medication I was given every day was for, I realised that I was HIV-positive."

Figure 11 below describes the variation in the percentage of adherence, according to the mode of disclosure. Adherence to ART can be seen to be influenced by the mode of disclosure of HIV status, with the level of adherence seeming to be low when the adolescent discovers their HIV status indirectly by themselves. The lowest adherence levels were observed among adolescents who had become aware of their HIV-positive status after having undergone HIV voluntary counselling and testing (VCT).
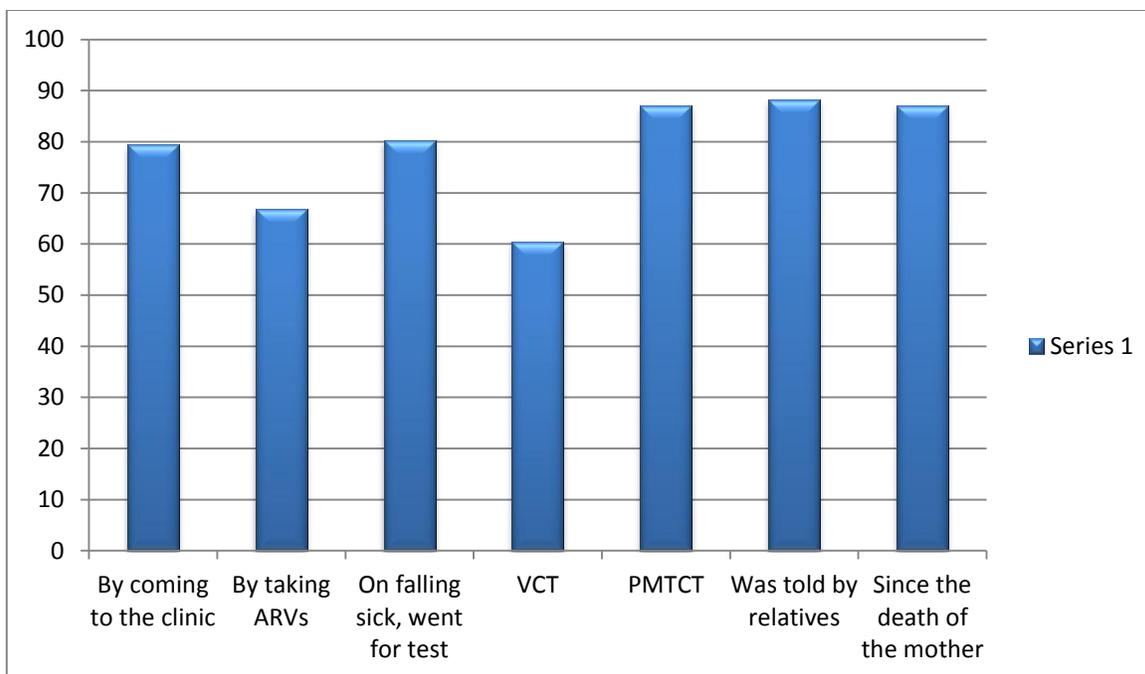
Figure 11. **Percentage of adherence mean in terms of mode of disclosure**

4.2.5. Feelings regarding the taking of ARVs

Besides the responses received regarding the above-mentioned mode of disclosure, the majority of participants reported that they had accepted being informed of their HIV-positive status, and were, consequently, comfortable about taking ARV drugs. One participant stated: "I am feeling fine, because if I did not come to the clinic to take ARV, I could not [be] living as I am now." Another participant said: "The reason why I was given this medication was because I was coughing too much. Now I am feeling better, and I like them."

Figure 12 below describes the proportion of participants who responded that they were feeling well (86.6%) and the proportion who stated that they did not feel well (13.3%).
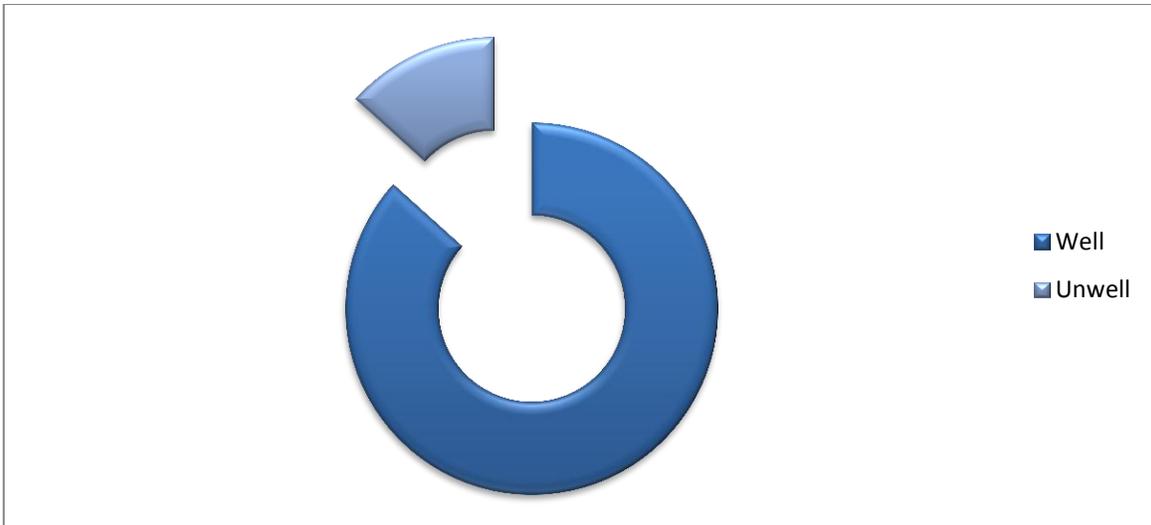
Figure 12. **Feelings regarding the taking of ARVs**

Figure 13 below describes the variation in the percentage of adherence according to the feelings expressed regarding the taking of ARVs. The adherence to ART seemed to be lower among the adolescents who were not comfortable regarding their HIV-positive status and about having to take ARV drugs.
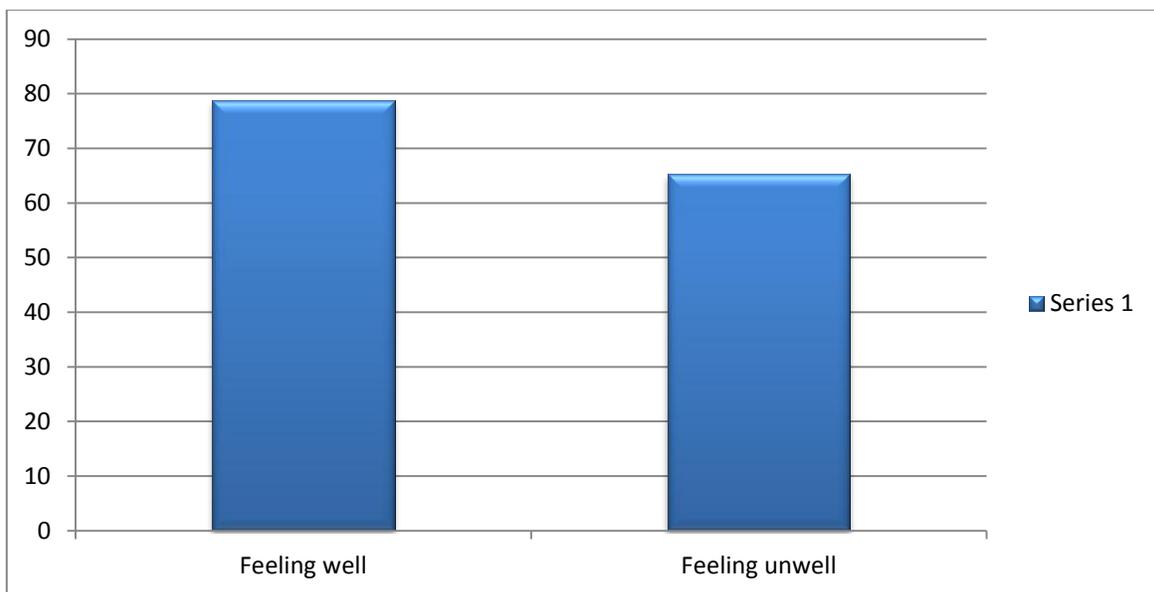
Figure 13. **Percentage of adherence mean in terms of feelings regarding the taking of ARVs**

4.2.6. Disclosure of HIV status to others (in terms of stigma)

Fears of being discriminated against, as well as of losing their friends after disclosing their HIV-positive status to them, had resulted in 30% of the participants not having disclosed their HIV status to anyone. Two of their responses were: "I do not want to disclose my HIV status to anyone because of fearing to lose my friends" and "I am not comfortable at all to tell other people about my status." A total of 46.66% of the participants stated that they were not willing to disclose their HIV status to other people than their close relatives. Some of them reported that they were comfortable enough to tell a limited number of close friends. The attitude of keeping their HIV-positive status as a strict secret even extended to the manner in which they kept their medications, with most of the adolescents (50%) keeping their tablets hidden in their bags. Many stated that they had to keep their medication in a very safe place, with some of them stating that they did so for security reasons, but others stating that they kept their ARVs in their bag in 'secret', in order to avoid letting other people know that they were taking ARVs. One of the participants stated: "I cannot take drug[s] when people are looking at me. I prefer to skip the dose if it is not possible to hide myself."

Figure 14 below describes the variation in the mean of adherence percentage according to fear of stigmatisation. Stigma consistently drove down the level of adherence to ART.
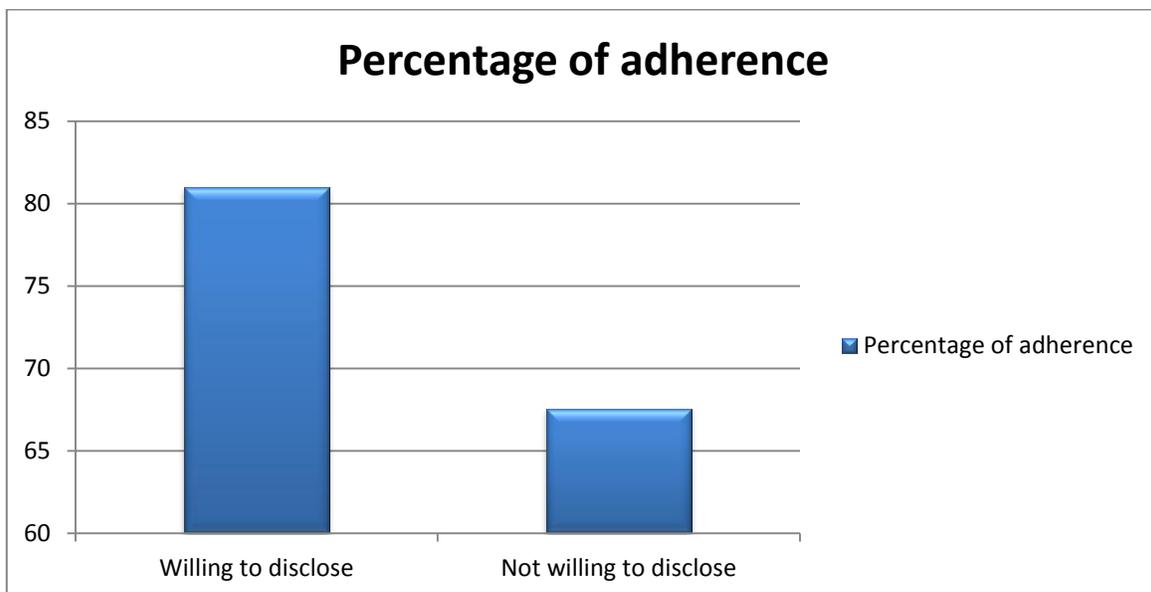
Figure 14. **Percentage of adherence mean in terms of willingness to disclose HIV status**

4.2.7   Support system

At least 33.3% of the participants stated that they attended the clinics alone, and another 40% stated that, if they were unable to attend the clinic, they had no one to assist them with collecting the ARVs at the clinic. They then had to miss out on the prescribed doses until they were themselves once more able to visit the clinic. The rest of the participants felt generally supported by their relatives, who accompanied them to the clinic, or who made themselves available to collect medicines for them when they were not able to attend the clinic. Most participants stated that they had been principally supported by an aunt or grandmother. Participants aged 17 and above had a tendency to attend the health facilities alone, because of not feeling comfortable enough to share their HIV-positive status with others. One participant commented: "If I am not able to come to the clinic for review or [a] refill, no one else can assist me."

Figure 15 below describes the variation in the percentage of adherence mean according to the nature of a 'treatment buddy'. The adherence level to ART seemed to be lower among adolescents who were supported by their grandmothers than it was among those who attended the clinic with their parents.
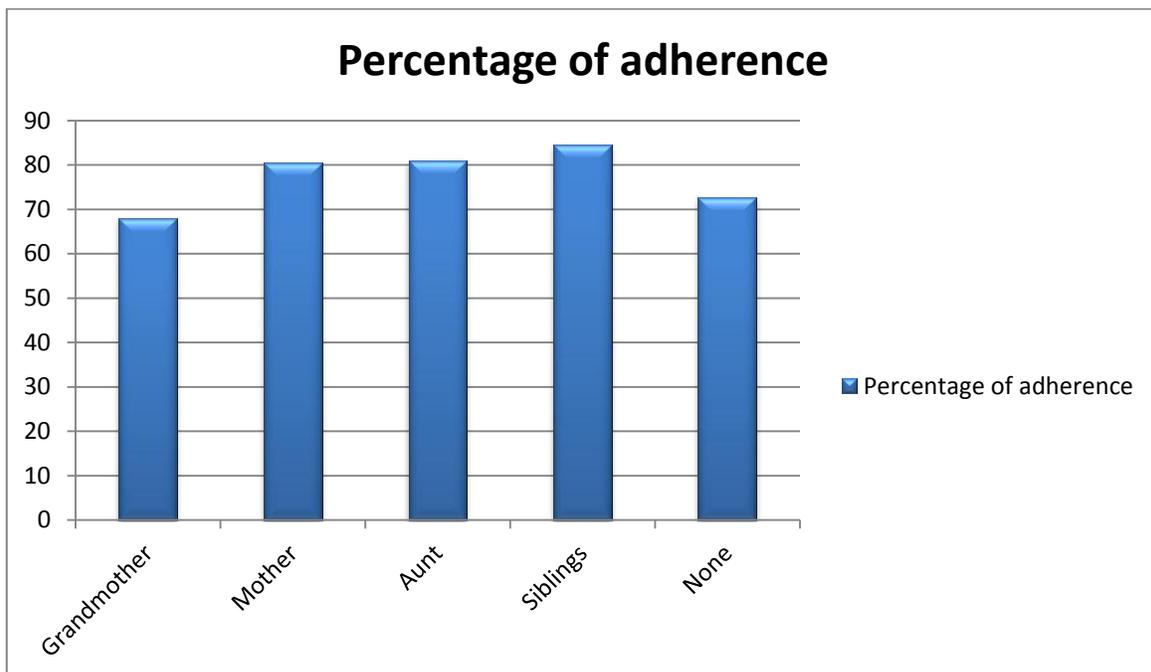
Figure 15. **Percentage of adherence mean in terms of nature of treatment buddy**

4.2.8. Medication side-effects

The most frequently reported side-effects experienced by 43.33% of the participants were: skin rashes; headaches; nausea and/or vomiting; and dizziness. In general, most of the participants declared that they had tolerated their treatment, and that they had not experienced any side-effect during their treatment. The occurrence of side-effects was also mentioned as a problem, because concerned participants were supposed to attend the health facility immediately after stopping their medication, as was mentioned by one participant: "I once experience[d] skin rash while taking my medication. I stopped them, and waited for the money to go to the clinic for assistance." The knowledge about side-effects and what to do when experiencing medicinal side-effects seemed to be limited and, in certain cases, it was even poor, especially where decision-making regarding attending the health facility for advice or assistance was concerned, with 23.3% of the participants responding that they were not aware of what to do when experiencing side-effects while taking ARVs. As one participant stated:

I do not know what to do, because I was never been [sic] told at the clinic, that is why I was once told to stop my medication while waiting for the review date to go to explain to the doctor.

Figure 16 below describes the variation in the percentage of adherence, according to the patients' experience of side-effects. The adherence level to ART was found to be adversely lower among adolescents not experiencing side-effects than it was among those experiencing side-effects.
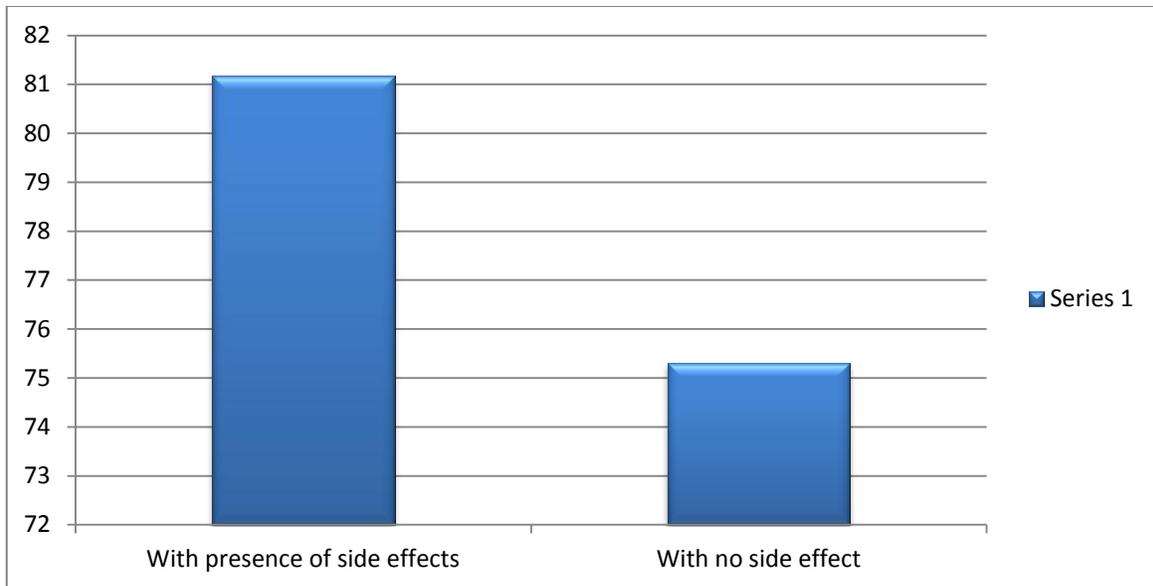
Figure 16. **Percentage of adherence mean in terms of side-effect experience**

4.2.9. Knowledge regarding HIV/AIDS and the taking of ARVs

Despite the finding that the participants in the study tended to be well-informed about HIV/AIDS and ARVs, 10% of them declared during the interview that they knew nothing about ARVs, whereas another 10% of the participants stated: "One day, I will be cured and stop [having] to take ARVs." The above-mentioned facts constitute a challenge to adherance to medication, as was explained by 30% of the participants, who declared: "I am not aware of risks or [of] what can happen to me if I stop to take [i.e. taking] ARVs." It was observed that the well-known modes of transmission of HIV were related to PMTCT. There seemed to be confusion about when to take the next dose of ARVs, when the time for taking it had already passed, with 20% of the participants declaring that they did not know what to do if they had forgotten to take their medication. They stated: "If I forget to take my treatment at the requested time, I will take it only [on] the following day, instead of taking the dose late."

Figure 17 below describes the variation in the percentage of adherence, according to the level of own knowledge. Adherence to ART seemed to be low among adolescents with sound knowledge of HIV and ARVs, and adversely high among adolescents with average knowledge of the above.
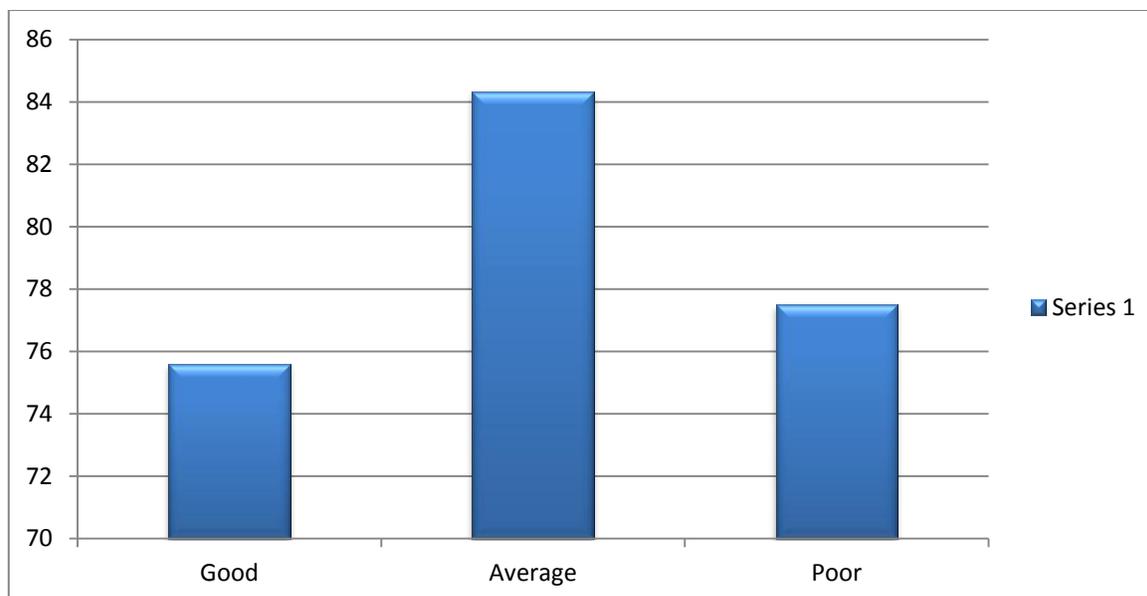
Figure 17. **Percentage of adherence mean in terms of knowledge regarding HIV and ARVs**

4.2.10. Interaction between patient and health care providers

Apart from the 10% of participants who declared that they were not comfortable with their health care providers, the majority stated that they were both satisfied with, and had confidence in, their respective health care providers. Most of the participants reported that they were satisfied with the manner in which they were treated at the facility, and that they felt confident with their health care provider, because "they [i.e. the health care providers] are not showing [up] their [i.e. the patients'] ignorance", as one of the participants stated. The large majority of the participants who were residing near the health facilities in question were able to attend the facility monthly. However, in some cases, some participants (23.3%) had to travel more than 15 km to the clinic, and experienced difficulties with having to pay the transport costs.

Figure 18 below describes the variation in adherence according to the distance required to be travelled between the health facility and the participant's home. Adherence to ART seemed to decrease with the distance that the participants were based from the health facility concerned.
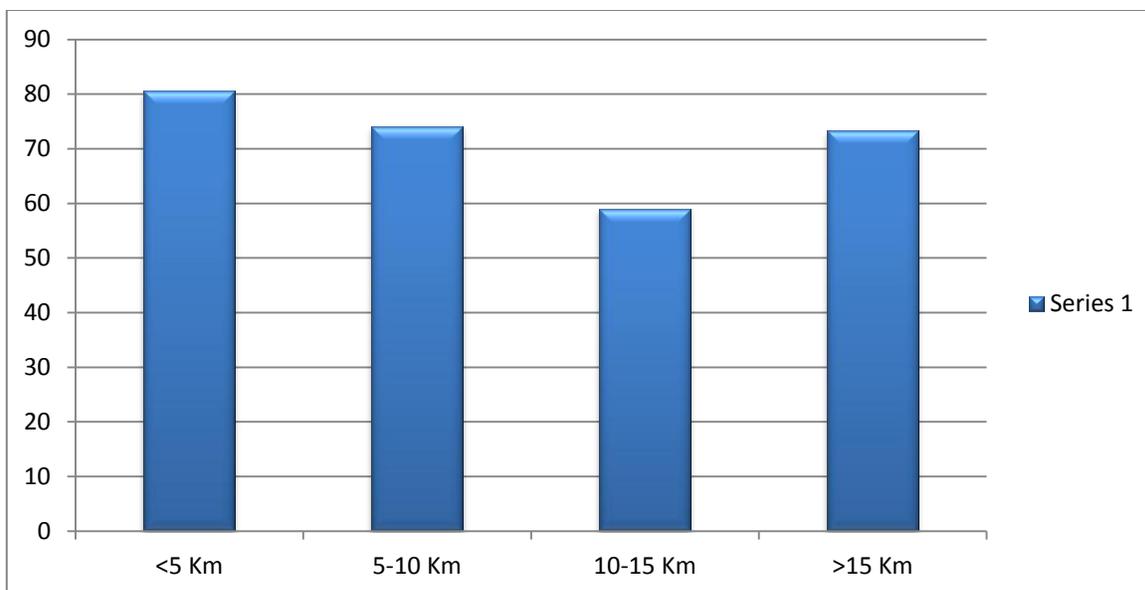
Figure 18. **Percentage of adherence mean in terms of distance of the patient from the health facility**

4.2.11. Medication interaction with lifestyle and social habit

In general, the participants indicated that they appreciated their medication for helping to maintain their wellness and survival. They generally stated that the taking of ARVs did not interfere with their adolescent lifestyle, and that it did not much impede their social habits. However, 3.33% of the participants declared that the "time to take my medication is not practical with [i.e. for] my daily lifestyle". Some of the participants raised the problem of having to adhere strictly to the prescribed time of taking their medication, as prescribed by their health providers. One of the participants described the problem as follows: "I regularly missed one of my daily doses, because of the [i.e. its] correspondence of [i.e. with] my time to go to work." Another participant stated: "I once missed my evening dose, because I came back late from school."

The problem of having to wait a long time at the health facility was cited by some participants (26.6%) as being a major challenge to adhering to the medical review or to the ARV refill schedule date. In connection with said issue, one participant stated: "I cannot attend school properly, because I am always spending ... all day at the clinic when I am coming for review."

Another participant stated: "Sometimes I even give priority to school, especially when we are writing our exams."

5.   DISCUSSION

5.1   Coverage of the current study

The current study was conducted in order to identify the main factors (barriers) affecting HAART adherence among adolescents in selected Botswana clinics, so that recommendations could be proposed for improving adherence to ART.

5.1.1. Barriers to adherence to the ART regimen

The study examined several barriers to adherence described in the literature, by conducting a face-to-face interview with adolescent patients who had taken ARVs for more than one year. Some of the barriers discussed as affecting adolescent HAART adherence included stigma, the poorly conducted process of disclosure and social support, inadequate knowledge regarding both HIV and ARVs, the side-effects of having to take the medication, the distance of the patient from the health facility and the long waiting time endured at clinics, and the effect of having to take the medication on the patient's social lifestyle.

5.1.2. Percentage of adherence among adolescents studied

The adherence rates found ranged between 44% and 94%, with the adherence percentage mean being 76.9%, which was less than the required 95% recommended in the literature to support the successful administration of ART. This percentage of adherence was also less than the reported 83% (Nwokike, 2004) that was found in the public health sector, but more than the reported 54% (Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex & Marlink, 2003) that was found in the private sector, with both of these research studies having been conducted in Botswana. The reason for male adolescents (72.4%) being less adherent than were their counterpart female participants (80.4%) has yet to be revealed, unless the lack of adherence was related to the length of time that passed since starting treatment, which would imply that adolescents, especially female participants, are more likely to be adherent at the start of treatment.

The percentage of adherence was also found to be good with adolescents who were around the age of thirteen, and dropped progressively until they reached the age of nineteen, due probably to adolescent psychological growth, or to a decrease in adherence that was associated with the length of time over which ARVs were taken (i.e. pill fatigue). The above might also be the reason for the observed percentage of adherence being poor among participants attending senior secondary school.

5.1.3. Inadequacies in the disclosure process

The disclosure process appeared not to be being done in time and properly, with most participants discovering their HIV status themselves, either due to them being required to attend the health facility on an ARV scheduled day, or by them discovering why they had to take their prescribed medication. The mean age of discovery of own HIV-positive status was 12 years. As was previously described in the relevant literature, health care workers and caregivers were reluctant to disclose to a child or an adolescent that they were HIV positive, due to the fear that their patients would have of their own stigmatisation and of the discrimination that would be likely to be perpetrated against them (Botswana, 2012, p. 71).

According to the literature, one of the difficulties experienced during ART in children and adolescents have to cope with the disclosure process, which is supposed to be undertaken according to the sound judgement of support that is made available to the adolescent. The questions to be asked are when, where and how the disclosure should be done. According to the Botswana ARV guidelines, providing children and adolescents with age-appropriate information about their illness is an essential part of HIV care, and, in coordination with the family and other clinic staff, is the responsibility of the treating practitioner (Botswana, 2012, p. 73).

Disclosure of HIV status to adolescents should be considered as forming a process, rather than consisting of a one-time event. The levels of adherence were found to be good in the current study, with the disclosure process starting relatively early, when the patient was around the

age of ten, and then dropping progressively from when it took place from the age of eleven to a later age. The level of adherence was also found to be critical during the first two years after the disclosure, and the participants in the study were found to adhere to their treatment when the disclosure was undertaken by relatives or during PMTCT, compared with when adolescents discovered their HIV status by themselves, due to them being required to take ARVs, or after they had undergone voluntary HIV testing and counselling.

The participants stated that they were not comfortable with disclosing their HIV status to another person than to a close relative. The large majority of them were reluctant to disclose their HIV status at school, with only a few participants being willing to disclose their HIV status to their close friends. The result of the study showed that adolescents who were not willing to disclose their HIV status to others also tended to have a lower level of adherence to ART than did their counterparts who were open about their HIV status.

5.1.4. Obtaining social support from relatives

People living with HIV in general and those who take ARVs in particular, require support from their relatives and circle of friends and acquaintances. In the process of preparing a patient for starting to take ARVs, an important element is the designation of a 'treatment buddy' to play a role in supporting the patient all along in their treatment. Adolescents are particularly in need of such a buddy, because of them being more likely to have a fragile mental state that is characterised by denial and the fear of infection, as well as by the impact that it will have on their future. They seem to require more support than do adults, because they still have a long way to go with their treatment, so that sharing their status with close friends or with a close teacher, for example, is likely to be important to, and supportive for, them. Supported adolescents might also avoid experiencing an attitude of low self-esteem.

Social support from their relatives was found to be important in the current research study. Adolescents who attended the health facility accompanied by a direct relative, like their mother, aunt or a sibling, were found to adhere better to their treatment than did those who were accompanied by a grandmother, or did those coming alone to the facility. Unfortunately,

the majority of young infants and adolescents tended to live with one of their grandmothers in the rural areas, which constituted a permanent issue affecting adherence to ART in the rural area of the country.

5.1.5. Tolerance of ARV regimen by patients

The present study showed that the ARV regimen in Botswana was relatively well tolerated by the large majority of patients, thus the experiencing of side-effects was not considered as one of the major barriers to adherence. However, the adolescents not experiencing side-effects during their HIV treatment were, on the contrary, found to be less adherent to the treatment than were those in the other group. The above might be explained by the patients' lack of knowledge about ARVs, with the adolescents not being interested in either knowing the side-effects, nor what to do when they experienced them. At the same time, the health care providers, especially the pharmacists, seemed to neglect to use each visit that the patients paid the facility as an opportunity to explain and to inform them about what they could expect in terms of possible side-effects of the medication taken. Close attention seemed to be paid to the adherence counselling of patients only if a problem was detected.

5.1.6. Lack of knowledge regarding adherence to the ART regimen

The lack of knowledge regarding adherence to the ART regimen also seemed to affect the notion of what to do if one forgot to take ARVs at the prescribed time, which is essential information to provide when dispensing ARVs. The majority of the participants were found not to have experienced side-effects during their treatment. Knowledge regarding side-effects seemed not to have been sufficiently covered, with most of the participants still ignoring the possibility that they might experience side-effects, and not concerning themselves about ensuring that they knew what to do if they did experience them.

5.1.7 Overall problems encountered in securing compliance with the ART regimen

In general, the relationship between adolescents and health care workers did not seem to be problematic. However, the long-time (up to "all day") that they were expected to wait for

treatment at the clinic, which impacted on their daily habits, especially school attendance, could have adversely affected their clinic and/or refill attendance. In addition, the participants in the study who stayed far from the health facility that they had to attend seemed to be less adherent to their treatment than were those who stayed close to the health facility, due to the unavailability of transport for the former patients. Said two problems that were revealed in the current study might constitute barriers for the adolescents needing to attend the clinic for a consultation or for a refill of their ARVs. Implementing a more efficient appointment scheduleling process and having a sufficient number of trained staff available to allow for the competent handling of patients might assist with balancing the progressively increasing workload and with shortening the waiting time experienced.

6.   CONCLUSION AND RECOMMENDATIONS

6.1   Objective of the current study

Adolescents constitute a special segment of HIV-positive patients requiring particular attention from health care providers and from the entire National HIV/AIDS Programme, because of their particular psychological condition that inclines them not to adhere to the taking of ARVs. The main objective of the current research study was to find out why adolescents do not adhere to taking ARV drugs in selected clinics in Botswana.

6.2   Deviation from the standard protocol regarding disclosure of HIV-positive status

The entire process of when, where and how to disclose HIV status seemed not to follow that recommended in the literature. The majority of participants were found to learn about their HIV-positive status themselves through other ways than being told by caregivers or health care providers. Such a process could be seen to affect negatively the rate of adherence, and might also be the reason for the participants in the current study experiencing stigma that showed itself in them not being comfortable about disclosing their HIV status, and in the worsening of their poor adherence to their treatment.

6.3   Barriers encountered to adherence to ART regimen

Adolescents who were accompanied to the clinic by their grandmother and those attending the clinic alone tended to be less adherent to their treatment. Other factors, such as distance from the health facility and feelings regarding the taking of ARVs, were found to affect the rate of adherence negatively. However, contrary to common expectations, adolescents with a good level of knowledge and those not experiencing side-effects seemed to be less adherent to their prescribed treatment. Due to the distance to the health facilities, and the waiting time that the participants were required to spend there, some adolescents also expressed concerns regarding having to adhere to the schedule follow-up appointment, as doing so interfered with their social habits, like having to attend school and work.

6.4   Recommendations for health care workers

Based on the above findings, it is recommended that health care workers should:
- continuously evaluate the level of maturity of young HIV-positive patients and discuss, at the appropriate moment, where and how to disclose their status to them;
- continuously insist on the importance of disclosing the HIV-positive status of patients to them, with the main objective of assisting adolescents in choosing should be their treatment buddy;
- encourage HIV-positive adolescents during each of their clinic visits to take their ARVs, and reinforce their knowledge about HIV and ARVs;
- discuss with the adolescent's parents the importance and the choice of a treatment buddy; and
- assist caretakers to teach young children the names of their medicines and how they should be taken. They should also set aside sufficient time during a follow-up visit to review the adolescent patient's knowledge regarding HIV and ARVs and to teach them that their medicines are assisting to restore health by increasing the number of CD4 cells. The caretakers should also actively insist on the fact that young patients can live healthy lives and that they are as equally capable of thinking about, and planning, their lives as are HIV-negative adolescents.

6.5   Recommendations for the ARV rollout programme

Recommendations for the ARV rollout programme include:
- extending the ARV dispensing service at health posts that are close to the community, in order to address the barrier of both distance and congestion at the clinic; and
- attaching special consideration to the peer support of adolescents in the rural areas, in line with the support that is recommended for, and organised in, towns. Rural health facilities must also be supported to implement HIV-positive peer support networks, such as adolescent clubs, where the HIV-positive adolescents can meet and support one another. Discussion within peer supports networks must be extended to questions related to sexual and reproductive health.

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<div align="center">**ADDENDA**</div>

Addendum A Tables of results

I.   Demographic data

Table 2

Population distribution by age and sex

Age in Years	Males	Females	Total
18 years	1	0	1
16 years	0	1	1
16 years	1	0	1
14 years	0	1	1
15 years	0	1	1
15 years	1	0	1
13 years	0	1	1
13 years	1	0	1
13 years	0	1	1
16 years	1	0	1
17 years	0	1	1
13 years	0	1	1
14 years	1	0	1
14 years	1	0	1
15 years	1	0	1
13 years	0	1	1
14 years	0	1	1
16 years	0	1	1
14 years	0	1	1
15 years	0	1	1
15 years	1	0	1

16 years	0	1	1
20 years	0	1	1
20 years	0	1	1
13 years	1	0	1
20 years	0	1	1
17 years	0	1	1
20 years	1	0	1
19 years	1	0	1
18 years	1	0	1
Total	13	17	30

Table 3

Distribution of population level of education by sex

Education level	Male	Female	Total
Primary	4	4	8
Secondary Junior	6	10	16
Secondary Senior	3	1	4
Tertiary	0	0	0
Never Been to School	0	2	2
Total	13	17	30

II.   Stigma and Disclosure of HIV status

Table 4

Length of been aware of HIV status by sex

Duration in years	Male	Female	Total
1-2 years	3	8	11
3-4 Years	4	2	6

| >5 years | 6 | 7 | 13 |
| Total | 13 | 17 | 30 |

Table 5

Age of disclosure by sex

Age in Years	Males	Females	Age of Disclosure
18 years	1	0	15
16 years	0	1	10
16 years	1	0	12
14 years	0	1	12
15 years	0	1	13
15 years	1	0	10
13 years	0	1	13
13 years	1	0	9
13 years	0	1	7
16 years	1	0	15
17 years	0	1	6
13 years	0	1	9
14 years	1	0	7
14 years	1	0	13
15 years	1	0	18
13 years	0	1	11
14 years	0	1	10
16 years	0	1	13
14 years	0	1	12
15 years	0	1	13
15 years	1	0	6
16 years	0	1	19

20 years	0	1	20
20 years	0	1	9
13 years	1	0	18
20 years	0	1	15
17 years	0	1	16
20 years	1	0	14
19 years	1	0	12
18 years	1	0	12
Total	13	17	

Table 6

Mode of disclosure

	Male	**Female**	**Total**
I was not feeling well then I went for HIV test	10	4	14
I was always brought to the clinic during ARV clinic schedule	1	3	4
Since the death of my mother	0	1	1
When I discover that I was taking ARVs	1	3	4
I was told by relatives	1	3	4
I was told at the clinic	0	0	0
Voluntary Counselling and Testing	0	2	2
During PMTCT	0	1	1
Total	13	17	30

Table 7

Feeling toward taking ARV

	Male	**Female**	**Total**
Well	10	16	26
Not Well	3	1	4

Total	13	17	30	

Table 8

Disclosure of HIV status to others

	Males	Females	Total
Who have you told about your status			
Parents	3	3	6
Aunty	0	3	3
Siblings	2	6	8
Garand Mother	0	0	0
Close Friends	1	1	2
School teacher	0	2	2
No one	7	2	9
Total	13	17	30
Who else are you willing to disclose to			
Siblings	2	2	4
Aunty/Uncle	2	1	3
Friends	0	8	8
Teacher	1	0	1
No one	8	6	14
Total	13	17	30
Are you comfortable to disclose your status to a friend			
Yes	4	14	18
No	9	3	12
	13	17	30

III.   Support system

Table 9

Support system

	Male	Female	Total
Who is accompanying you to the Clinic			
Parents	2	4	6
Grand Mother	2	3	5
Aunty	1	6	7
Siblings	1	1	2
Teacher	0	0	0
No one	7	3	10
Total	13	17	30
If not around, who else			
Parents	0	2	2
Grand Mother	2	4	6
Aunty	2	4	6
Siblings	2	0	2
Neighbour	1	1	2
Friend	0	0	0
No one	6	6	12
Total	13	17	30

IV.   Medication side-effects

Table 10

Side-effects

	Male	Female	Total
Experienced Side-Effects			
Skin Rash	2	1	3
Headache	1	1	2
Nausea/Vomiting	1	1	2
Swollen Body	0	1	1
Coughing/Dyspnoea	0	1	1
Dizziness	3	1	4
No side-effects	6	11	17
Total	13	17	30
Expecting side-effects			
Skin Rash	4	5	9
Headache	0	0	0
Nausea/Vomiting	1	1	2
Dizziness	2	3	5
Insomnia	0	0	0
Dyspnoea	0	0	0
Do not know	6	8	14
Total	13	17	30
What to do if side-effect			
Stop the treatment	0	0	0
Stop treatment and go to the clinic	3	0	3
Continue treatment and go to the clinic	4	6	10
To go to the clinic	4	6	10
Do not know	2	5	7
Total	13	17	30

V.   **Adequate information or knowledge**

Table 11

Knowledge about HIV/AIDS and ARVs

	Male	Female	Total
What are risks of HIV			
Unprotected sex	6	3	9
Sharing a razor	1	2	3
Blood contact	3	5	8
Through breast milk	2	5	7
During delivery	1	2	3
Total	13	17	30
What do you know about HIV medications			
They are taken every days	1	2	3
They are not curing HIV	1	4	5
They are taken lifelong	3	0	3
They are reducing the rate of HIV	1	4	5
They are taken by someone who have HIV	0	1	1
They are improving the rate of CD4	2	2	4
They are prolonging life	2	3	5
They are not taken with alcohol, drugs or traditional medicines	1	0	1
I do not know	2	1	3
Total	13	17	30
What are the risks of stopping ARVs			
One can lose life if stopping ARVs	3	3	6
ARVs are not curing HIV	3	9	12
One day I will be cured and stop ARVs	1	2	3

I do not know	6	3	9
Total	13	17	30
What to do if you forget to take your medication			
I have to tell relatives so that they can remind me	0	2	2
I will take the following day	1	1	2
I will go to the Clinic the following day	3	4	7
I will take the dose as soon when I remember	7	6	13
I do not know	2	4	6
Total	13	17	30

VI.   Interaction with Health Service

Table 12

Interaction between patient and health care provider

	Male	**Female**	**Total**
Do you feel you can ask any questions from your health provider			
Yes	11	16	27
No	2	1	3
Total	13	17	30
Do you feel confident with him			
Yes	12	17	29
No	1	0	1
Total	13	17	30
Are you satisfied with the manner which the health staff assist you			

Yes	13	17	30
No	0	0	0
Total	13	17	30

VII.   Medication interaction with lifestyle and social habit

Table 13

ARV interaction with lifestyle and daily habit

	Male	Female	Total
Where do you keep your medication			
On top of the table	1	5	6
On top of the wardrobe	1	2	3
In the drawer	3	2	5
In the bag	8	7	15
In a very safe place	0	1	1
Total	13	17	30
Is the time of taking your medication practical			
Yes	13	16	29
No	0	1	1
Total	13	17	30
Interaction on other aspects of the lifestyle			
Interfering with the time to go to church	0	1	1
Interfering with the time to go to school	3	3	6
Interfering with the time to go to work	2	1	3
No interaction at all	8	12	20
Total	13	17	30

VIII.   Other interactions

Table 14

Other interactions

	Male	Female	Total
How far are you staying from the Clinic			
< 5 km	9	9	18
5-10 km	1	2	3
10-15 km	1	1	2
>15 km	2	5	7
Total	13	17	30
Are you able to come to the Clinic every Month			
Yes	9	15	24
No	4	2	6
Total	13	17	30
Is there anyone else who can collect ARVs for you if not able to come to the clinic			
Yes	13	17	30
No	0	0	0
Total	13	17	30
How is your HIV status affect your social habit			
I cannot attend school properly because I am always spending the all day at the clinic when I am coming for review	5	3	8
No change at all	8	14	22
Total	13	17	30

—

Table 15

Percentage of adherence and factors affecting adherence

Age (years)	Male	Female	Adherence (%)	Length of disclosure (years)	Mode of disclosure	Distance (Km)
18	1	0	90	3	A	<5
16	0	1	87	6	B	5-10
16	1	0	69	4	C	<5
14	0	1	91	2	C	5-10
15	0	1	89	2	A	<5
15	1	0	67	5	C	<5
13	0	1	90	1	D	<5
13	1	0	94	4	C	<5
13	0	1	89	6	C	<5
16	1	0	78	1	C	<5
17	0	1	90	9	C	<5
13	0	1	68	4	E	>15
14	1	0	71	7	C	<5
14	1	0	57	1	C	<5
15	1	0	71	7	E	<5
13	0	1	80	2	A	>15
14	0	1	86	4	E	<5
16	0	1	71	3	E	<5
14	0	1	44	2	E	5-10
15	0	1	91	2	C	<5
15	1	0	75	9	C	>15
16	0	1	92	7	D	>15
20	0	1	63	1	F	>15
20	0	1	87	11	G	<5

13	1	0	83	5	D	>15
20	0	1	91	5	C	<5
17	0	1	59	1	A	>15
20	1	0	67	6	E	>15
19	1	0	58	7	F	10-15
18	1	0	61	6	E	10-15
Total	13	17	X 76.96	X 4.3		

A: by coming to the clinic during ARV clinic

B: since the death of my mother

C: I was always sick then went for HIV test

D: I was told by relatives

E: By taking ARVs

F: VCT

G: PMTCT

Addendum B   **Study questionnaire**

INTERVIEW SCHEDULE

a) Attitude towards their HIV status and medication

(i)   How long have you been aware about you HIV status?

(ii)   How did you find it out?

(iii)   What is your feeling towards taking ARV?

b) Disclosure

(i)   Who have you told about your status? For example: family member, friend, at school.

(ii)   Who else are you willing to disclose to?

(iii)   Are you comfortable to disclose to a friend that you are taking HIV medication?

c) Support system

(i)   Who is accompanying you to the clinic for medical review?

(ii)   If that person is not available, who else can be there for you?

d) Side-effects

(i)   What side-effect have you experienced while on ARV?

(ii)   Do you know what side-effect to expect from ARV?

(iii)   Do you know what to do if you experience side-effect?

e) Adequate information or knowledge

(i) What are risks of HIV infection?

(ii) What do you know about HIV medication?

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(iii)What are risks of stopping HIV medication?

(iv)Do you know what to do if you forget to take your medication?

f) Interaction between patient and client provider

(i)   Do you feel you can ask any questions from your health provider?

(ii)   Do you feel confident with him?

(iii)   Are you satisfied with the manner in which the health staffs assist you?

g) Interaction of medication to lifestyle and daily habits

(i)   Where do you keep your medication in the house? At boarding school?

(ii)   What time of the day do you take your medication? Is it practical for you?

(iii)   Is there any other aspect of your lifestyle that is interacting with your time of taking your medication?

h) Any other

(i)   How far do you live from the clinic?

(ii)   Can you get to the clinic easily and are you able to come every month?

(iii)   If you are sick and not able to come to the clinic, is there anyone who can fetch the medication for you?

(iv)   How is your HIV status or your medication affecting your social habits?

i) Demographic factors

(i)   What is your age?

(ii)   What is you gender?

(iii)   What is you education level?

Addendum C Consent for research

	STELLENBOSCH UNIVERSITY
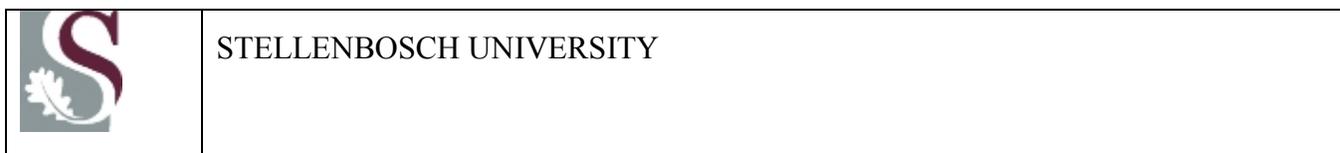
PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

TITLE OF THE RESEARCH PROJECT:

Factors that affect adherence to antiretroviral therapy among HIV/AIDS Adolescent patients at selected Palapye Clinics

What is RESEARCH*?*

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

What is this research project all about?

The research is projecting to identify main reasons influencing adolescents to not taking correctly their ARV drugs in order to assist health care workers to improve adherence counselling before and during the ARV treatment

Why have I been invited to take part in this research project?

You have been invited to take part to this research project because your age is corresponding to the age group defined by the study and you are collecting ARV drugs in this clinic today

Who is doing the research?

I am Doctor Kambale, I am based at Maokatumo clinic but I am also consulting patients at Maunatlala and Lerala clinic, this research project is part of my study, I am doing distance learning from Stellenbosch University in South Africa, and I will be assisted by Mrs Neo Mothusi who is the counsellor in the clinic.

What will happen to me in this study?

I will be assisted by the counsellor, and together we will invite you to seat in this office and we will ask you some questions about how you are taking your ARV drugs, we expect you to be as open as possible and feel free to respond to our questions, and at any time you can tell us to stop the conversation. We will also need to count your remaining pills and compare the number to the number of pills given to you during the last visit to the clinic, that will assist us to have an idea of how many pills did you take during this period. You have to know that your identity will not be recorded anywhere, we only need to know your opinion about your treatment. After the conversation I will keep all the information I my secured laptop where no one else will accede to the information, the conversation may take 30 to 40 minutes

Can anything bad happen to me?

You know, every things or conversation related to HIV may be misunderstood and mentally frustrate you, that why we are together with your counsellor who learned to understand you since more than a year now before and during your treatment. But it is only a conversation; we will not use anything which can harm you physically or mentally. We will ensure your safety and comfort through the process.

Can anything good happen to me?

Yes, the study may assist us health care workers to understand patients in your age group in order to improve our ability to continue supporting you all along your treatment, which is an important part of your treatment because support is all you need to maintain a good adherence to your medication.

Will anyone know I am in the study?

No, any one will know, as I told you I will keep everything in my secured laptop, and will report all information to the University but without mentioning, neither your identity nor the clinic where the information is coming from.

Who can I talk to about the study?

You can contact your local counsellor any time; if he/she cannot assist you he/she will contact me.

What if I do not want to do this?

It is your right to refuse to take part to the study even if your parents have agreed, but that will not affect your future treatment or the relationship with us.

Identification of investigators

If you have any questions or concerns about the research, please feel free to contact

Dr. HerveNzerekaKambale (Principal Investigator)

Maokatumo Clinic, P.O. Box 153, Maokatumo

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Dr. Greg Munro (Study Leader)

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Mrs Neo Mothusi (aid counsellor)

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Ms Nelly Moupo (aid counsellor)

Maunatlala Clinic, P.O.Box 71 Palapye

Tel (work): 4958235

Cell: 71408553

Mr WaboTathayaone (aid counsellor)

Lerala Clinic, P.O. Box 54 Lerala

Tel (work): 4954019

Cell: 75478611

Do you understand this research study and are you willing to take part in it?

YES	NO

Has the researcher answered all your questions?

YES	NO

Do you understand that you can pull out of the study at any time?

YES	NO

_____   _____

Signature of Child   Date

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CONSENT TO PARTICIPATE IN RESEARCH

Factors that affect adherence to antiretroviral therapy among HIV/AIDS Adolescent patients at selected Palapye Clinics

You are asked to participate in a research study conducted by Dr. HerveNzerekaKambale, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. The result of this research study will *be contributed to thesis.* You were selected as a possible participant in this study because you are aged between 18-20 years and you are taking antiretroviral drugs since more than a year.

1. **PURPOSE OF THE STUDY**

The purpose of this research study is to identify reasons influencing poor adherence to antiretroviral treatment among adolescent patients

2. **PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following things:

Location

To be interviewed in a private room respecting your confidentiality

Consent procedures

After introducing ourselves and explaining to you all the procedure, You will be given an information sheet explaining and describing briefly the study and its objectives, you will be allowed to ask questions or request more clarifications before to give us a verbal and written consent

Interview

After giving your consent, a face-to-face interview will be conducted by me, assisted by the local counsellor who will help me by explaining everything in Setswana if you have difficult to talk in English.

Duration

The length of the interview will be approximately 40 minutes

3. POTENTIAL RISKS AND DISCOMFORTS

As any conversation related to HIV/AIDS, you cannot feel comfortable to answer some personal questions during the interview, that is also the reason why the interview is conducted with the local counsellor who has been with you in this facility for long time. And you can also feel free to not respond or stop the interview at any time, and you have to know that it will not affect your future treatment.

As I say previously, HIV field is very sensitive; if you feel that we ask you something which is personal which may frustrate you, you are free to ask us to terminate this study.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Description of reasons contributing to poor adherence to antiretroviral treatment among adolescent should contribute to the improvement of adherence counselling before and during the treatment which is one of the factor contributing to the success of antiretroviral therapy.

The success of the antiretroviral therapy will improve the quality of life of adolescents and will reduce the transmission of the disease among the most productive and active age group of the society.

5. PAYMENT FOR PARTICIPATION

Participants to this study will not receive any form of payment

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of information obtain from you will be kept in a locked computer, your name will not be mentioned anywhere nor the clinic where the information was obtained. No other person will have access to the computer password, and all information will be deleted three months after the end of the study. There will be no way of identifying that you have participated in this study.

At the end of the study, encoded result will be submitted to the Africa Centre for HIV/AIDS Management and Ministry of Health of Botswana.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

At any time during the interview, if we observe that you are becoming frustrated we can decide together with the counsellor to terminate this interview.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact

Dr. HerveNzerekaKambale (Principal Investigator)

Maokatumo Clinic, P.O. Box 153, Maokatumo

Tel (work): 4958433

Cell: 75420524

Dr. Greg Munro (Study Leader)

Tel: 0027 836292567

Mrs Neo Mothusi (Co-Investigator)

Maokatumo Clinic, P.O. Box 153, Maokatumo

Tel (work): 4958433

Cell: 71662900

Ms Nelly Moupo (Co-Investigator)

Maunatlala Clinic, P.O.Box 71 Palapye

Tel (work): 4958235

Cell: 71408553

Mr WaboTathayaone (Co-Investigator)

Lerala Clinic, P.O. Box 54 Lerala

Tel (work): 4954019

Cell: 75478611

9.   RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms MaléneFouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant*] by [*name of relevant person*] in [Setswana*/English/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] were given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____   _____

Signature of Subject/Participant or Legal Representative   Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [his/her] representative _____ [*name of the representative*]. [*H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Setswana/*English/*other*] and [*no translator was used/this conversation was translated into _____ by _____*].

_____   _____

Signature of Investigator   Date

STELLENBOSCH UNIVERSITY

PARENTS/GUARDIANS CONSENT TO PARTICIPATE IN RESEARCH

Factors that affect adherence to antiretroviral therapy among HIV/AIDS Adolescent patients at selected Palapye Clinics

You are asked to authorize your child to participate in a research study conducted by Dr. HerveNzerekaKambale, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. The result of this research study will *be contributed to thesis.* Your child was selected as a possible participant in this study because he is aged between 13-17 years and he is taking antiretroviral drugs since more than a year.

1. **PURPOSE OF THE STUDY**

The purpose of this research study is to identify reasons influencing poor adherence to antiretroviral treatment among adolescent patients

2. **PROCEDURES**

If you volunteer to participate in this study, we would ask your child to do the following things:

Location

To be interviewed in a private room respecting his/her confidentiality

Consent procedures

After introducing ourselves and explaining to you all the procedure, You will be given an information sheet explaining and describing briefly the study and its objectives, you will be

allowed to ask questions or request more clarifications before to give us a verbal and written consent to interview your child.

Interview

After giving your consent, a face-to-face interview will be conducted by me, assisted by the local counsellor who will help me by explaining everything in Setswana if you have difficult to talk in English and to support your child psychologically if he/she is not feeling comfortable with our questions. We will also need to count his/her remaining pills and compare the number to the number of pills given during the last visit to the clinic, that will assist us to have an idea of how many pills did he/she takes during this period.

Duration

The length of the interview will be approximately 40 minutes

3. POTENTIAL RISKS AND DISCOMFORTS

As any conversation related to HIV/AIDS, your child can not feel comfortable to answer some personal questions during the interview, that is also the reason why the interview is conducted with the local counsellor who has been with you in this facility for long time. And your child can also feel free to not respond or stop the interview at any time, and you have to know that it will not affect his/her future treatment.

As I say previously, HIV field is very sensitive; if you feel that we ask your child something which is personal which may frustrate him/her, you are free to ask us to terminate this study.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Description of reasons contributing to poor adherence to antiretroviral treatment among adolescent should contribute to the improvement of adherence counselling before and during the treatment which is one of the factor contributing to the success of antiretroviral therapy.

The success of the antiretroviral therapy will improve the quality of life of adolescents and will reduce the transmission of the disease among the most productive and active age group of the society.

5. PAYMENT FOR PARTICIPATION

Participants to this study will not receive any form of payment

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with your child will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of information obtain from him/her will be kept in a locked computer, his/her name will not be mentioned anywhere nor the clinic where the information was obtained. No other person will have access to the computer password, and all information will be deleted three months after the end of the study. There will be no way of identifying that you have participated in this study.

At the end of the study, reports not containing any of participant particulars will be submitted to the Africa Centre for HIV/AIDS Management and Ministry of Health of Botswana.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also tell to your child to not answer any questions you don't want him/her to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

At any time during the interview, if we observe that your child is becoming frustrated we can decide together with the counsellor to terminate this interview.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact

Dr. HerveNzerekaKambale (Principal Investigator)

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Dr. Greg Munro (Study Leader)

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[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative

_____   _____

Signature Legal Representative   Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [his/her] representative _____ [*name of the representative*]. [*H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Setswana/*English/*other*] and [*no translator was used/this conversation was translated into* _____ *by* _____].

_____   _____

Signature of Investigator   Date