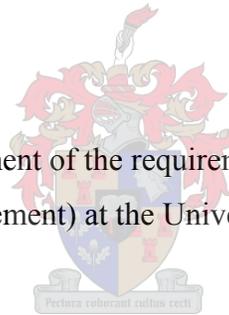# FACTORS WHICH AFFECT OPTIMAL ADHERENCE TO ANTIRETROVIRAL MEDICATIONS

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Assignment presented in partial fulfilment of the requirements for the degree Masters Philosophy (HIV/AIDS Management) at the University of Stellenbosch

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DECLARATION

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

February 2010

DEDICATION

I dedicate this work to my loving wife Evelyn Usman, whose support and encouragement never wavered all through the stress and demand of combining my work, family and academic pursuits.

ACKNOWLEDGEMENT

ABSTRACT

The advent of anti-retroviral therapy (ART) has bought hope and reprieve in a previously hopeless situation where there was no available drug to combat the virus with the result that AIDS deaths from chronic, untreated HIV infection became the major cause of morbidity and mortality especially in sub-Saharan Africa where the disease burden is highest. Since March 19, 1987, when the FDA approved Zidovudine for the treatment of AIDS, there has been great improvement in the prognosis and quality of life of HIV infected persons especially in sub-Saharan countries like Nigeria where the burden of HIV disease is high. Even though the treatment of HIV looked promising to all HIV sufferers, there were strict requirements for taking the ARVs, that meant patients had to be able to take the medication more than 95% of the prescribed time. The requirements also involved strict dietary restrictions that further made adherence to these medications very difficult indeed. In addition, the potential for side effects of the medications and its requirement for life-style modifications like abstinence from excess alcohol made sticking to the required regimen very cumbersome and rather patient unfriendly.

Therefore, as the use of ARVs became more popular and effective, so did the problem of non-adherence continue to fester and deteriorate even further. Therefore, the problem of lack of optimum adherence to ARVs is one that potentially threatens all the gains of the discovery and use of potent, life-saving ARVs. Hence, there is now a need to look at how best to improve adherence to ARVs in the most innovative, cost-effective and patient-friendly manner. This study argues for the use of simple, locally-driven adherence strategies that overcome the low literacy and excessive alcoholism that are major factors preventing optimal adherence to ARVs amongst patients.

OPSOMMING

Die intrede van anti-retrovirale behandeling het hoop en genade gebring aan 'n voorheen hopelose situasie waar daar geen behandeling beskikbaar was om die virus te beveg nie, wat daartoe gelei het dat VIGS, as gevolg van MIV-infeksie wat nie behandel is nie, die grootste oorsaak van sterftes in veral Sub-Sahara Afrika is. Sedert 19 Maart 1987, wanneer Zidovudine goedgekeur is vir die behandeling van VIGS, is daar 'n groot verbetering in die prognose en kwaliteit van lewe van MIV-geinfekteerde mense, veral in Sub-Sahara lande soos Nigerië waar die voorkoms van MIV hoog is. Hoewel de behandeling van MIV vir alle MIV-lyers belowend gelyk het, was daar streng vereistes vir die neem van anti-retrovirale behandeling. Daar was ook streng dieetkundige beperkinge wat die getrouheid tot die behandeling bemoeilik het. Die moontlike newe-effekte van die behandeling en nodige leefstyl veranderinge, soos byvoorbeeld weerhouding van oormatige alkohol gebruik, maak die behandeling redelik pasiënt onvriendelik.

Soos die anti-retrovirale behandeling meer gewild en effektief geraak het, het die probleem van ongetrouheid ook toegeneem. Die probleem rondom ongetrouheid tot behandeling bedreig alles wat deur die behandeling gebied kan word. Daar is nou 'n behoefte daaraan om getrouheid tot anti-retrovirale behandeling te bevorder in die mees innoverende, koste-effektiewe en pasiënt vriendelike manier. Die studie beveel eenvoudige, plaaslik gedrewe getrouheid-strategieë aan wat optimale getrouheid aan behandeling sal verseker.

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CHAPTER 1

INTRODUCTION

Adherence is the extent to which a patient's behavior coincides with the prescribed health care regimen determined through a shared decision making process between the patient and health care provider (Frank Miramontes as cited in Etienne & Amoroso, undated). While expanding access to HIV/AIDS treatment to resource-limited settings is recognized as a global health priority, there is concern that widespread antiretroviral use could lead to widespread drug resistance (Byakika-Tusiime, Orrell & Bangsberg, 2008). Limiting drug resistance is especially important in resource-limited settings where there are limited options for second-line regimens (Byakika-Tusiime et al.).

However, suboptimal adherence leading to incomplete viral suppression is the primary predictor of drug resistance. According to Byakika et al. our understanding of adherence to HIV antiretroviral therapy comes from studies in resource-rich settings. Therefore, there is a very critical need to evaluate factors that determine optimal adherence to antiretroviral therapy in resource-poor settings.

Moreover, studies have shown that consumption of more that 95% of prescribed doses was required to achieve an 80% probability of Viral Load (VL) less than 400 copies per milliliter at 24 weeks; with 90-95% adherence the probability of VL less than 400 copies per milliliter dropped to 50% (Bartlett & Gallant, 2007). Sustained viral suppression is usually associated with a rise in CD4 cell count to normal levels (immunologic improvement) after at least one year of therapy (AIDSRelief Training Slides, 2008). The critical role of adherence in the treatment of HIV has been demonstrated in clinical trials and clinical care settings. Antiretroviral (ARV) adherence is a strong predictor of biologic (virologic and immunologic) and clinical outcomes in HIV, including quality of life, HIV progression, hospitalizations, and death (http://journals.lww.com/jaids).

There are several factors that determine adherence. But, even intelligent and highly motivated individuals with medical backgrounds have difficulty with adherence (Dolin, Masur & Saag, 2003). A study in 36 medical students randomized to receive a twice –daily or thrice-daily placebo for 14 days found that the mean number of doses taken was only 71% of those prescribed, a result similar to that seen in AIDS or Epilepsy patients (Dolin et al. 2003). According to them, Health care providers cannot predict with great precision which patients will be adherent and which will not. Patient self-reports and pill counts also provide unreliable and inaccurate information. Socioeconomic factors, racial and ethnic background, and disease state, which seem as if they ought to be related to degree of adherence, generally are not.

According to Bartlett et al, guidance for improved adherence is:

- Establish patient readiness before initiating treatment

- Use a standardized approach to assess adherence

- Use the entire health care team to reinforce adherence messages

- Health care professionals are poor predictors of who will adhere

- Patients will usually over-report their adherence

- Adherence may decrease over time, becoming significantly worse at 6-12 months than it is initially

- Adherence is better in a medical setting than in a social service setting

- Patients need to understand that the regimen that most likely to succeed is the first one, although "rescue regimens" are becoming more effective.

- Address obvious issues of convenience: pill burden, frequency of daily administrations, food or fasting requirements, tolerance, pill size.

Other very important factors that have been found to affect adherence are distance from health care facility, alcoholism, and substance abuse, non-disclosure of HIV status, mental

illness, toxicity and side effect of medications. In addition, quality of ARV treatment preparation, food restrictions and availability of family support also affect optimal adherence.

AIM

The main aim of the study is to identify factors that determine optimal adherence to anti-retroviral medications with a view to making recommendations to improve upon the quality of care amongst PLWHAs.

OBJECTIVES

The objectives of the study are:

1. To highlight the importance of optimal adherence to ARVs

2. To identify the factors that determine optimal adherence to ARVs

3. To use data from this study to promote optimal adherence to ARVs.

4. To use the data from this study to influence the present model of HIV care.

CHAPTER 2

LITERATURE REVIEW

The scourge of HIV/AIDS in sub-Saharan Africa has led to widespread interventions with potent Anti-retroviral medications (ARVs) in a bid to counter the ravaging effects of the rampaging virus on the human host's immune system. After the United States Food and Drug Administration (FDA) licensed the use of Zidovudine to treat HIV disease on March 19th, 1987 initially in syrup form, several better, newer classes of ARVs have been developed and licensed to treat HIV/AIDS (www.fda.gov/ForConsumer). However, despite these successes in developing potent, life-saving ARVs, the problem of HIV infected patients adhering to taking these ARVs continues to pose a huge challenge to all caregivers across the whole spectrum of HIV care from diagnosis to treatment and all through the continuum of care. Therefore, it becomes very crucial for all stakeholders involved in the care, support and treatment of HIV positive patients to develop very potent, user-friendly interventions and processes that will enhance and improve optimal adherence to ARVs. Adherence means many things to many people. This is because apart from adherence to the medications, there is the need to also adhere to clinic visits and even to secondary prevention messages which ensures that the HIV infected patient does not transmit the virus to an uninfected patient through engaging in risky, unprotected sexual intercourse (AIDSRelief ART Training Slides on Prevention for Positives, PwP, 2009).

"Adherence is defined as taking doses of drugs and sticking to the treatment plan. It means taking the correct dose of drugs at the correct time and in the correct way (such as with the right type of food or fluid). It also means looking after drugs to make sure they are safe and effective to use. At an individual level, ARV treatment can allow ones immune system to recover so that illness is reduced and health and quality of life can be regained. Very high levels of patient adherence, greater than 95%, are required for ARVs to be effective and to prevent the emergence of resistant viral strains. This means missing no more than three doses a month for a twice daily regime, and maintaining that level of adherence year after year" (NAM, 2004) (Progress Report, WHO, 2007). Adherence has also been defined as the extent to which a patient's behavior

coincides with the prescribed health care regimen determined through a shared decision making process between the patient and the health care provider (Etienne & Amoroso, Undated).

Adherence to Antiretroviral Therapy (ART) means sticking to ART care and treatment.

- This means taking the correct doses at the correct times in the correct ways.
- All medications require adherence, but people forget doses or do not always take them at the right time.
- Once a patient begins taking ARVs, he or she must keep taking them every day, faithfully (100% of the time), and for the rest of his or her life in order for them to work effectively (Etienne &Amoroso).

However, it is very obvious that not all patients are able to adhere 100% and the virus is actually said to be very unforgiving in the sense that every dose missed is noted by the virus and it's genetic sequence of amino acids which promptly takes steps to evade or reduce the effect of the Anti-retroviral medications (ARVs) by changing its genetic makeup as it constantly replicates to produce new daughter virions which will end up producing a quasi-species of daughter viruses that differ from the parent or original wild-type virus to which the ARV was originally susceptible. This is how HIV drug resistance develops which ultimately leads to virological treatment failure. Poor adherence predicts virologic failure but it appears that the highest risk of resistance is with virologic failure in the face of relatively good but imperfect adherence (Bartlett & Gallant, 2008). Very importantly however, it has been demonstrated that there needs to be more than 95% (>95%) adherence to achieve 80% viral suppression (Bartlett & Gallant). According to these researchers, the ARV regimen the patient is taking also has an important role to play as several authorities have concluded that the initial regimen is the most important regimen because it is associated with the greatest probability of achieving prolonged viral suppression. In addition, drug resistance from poor or non-adherence may result in the failure of the immense global and national efforts to provide hope to people living with HIV" (www.cafod.org.uk).

In Africa, as we carry out expanded access to ARVs, there is the concern that widespread antiretroviral use could lead to wide spread drug resistance (Volberding, Sande, Lange, Green &

Gallant, 2008). Data from the developed world indicate that up to 10% of incident infections and 50% of prevalent infections carry resistant virus, which compromises treatment response (Volberding, Sande, Lange, Green & Gallant). According to them, suboptimal adherence leading to incomplete viral suppression is the primary predictor of HIV drug resistance.

Several studies have been undertaken to identify the factors that determine optimal adherence to ARVs. In a cross sectional study of 384 HIV/AIDS adult patients carried out at Moi Teaching Hospital and Referral Hospital in Eldoret, Kenya, the patients on ARVs were investigated for factors that affected their ARV drug adherence based on observing their timing of doses and keeping of clinic appointments for drug refills over a three month period. Data were collected from respondents using interviewer-administered questionnaires to patients and self-administered questionnaires by ten key informants (nurses and clinicians in charge of the HIV/AIDS clinic) selected by purposive sampling. Results from this study were that only 43.2% adhered to the prescribed time of taking drugs. The most commonly cited reasons for missing the prescribed dosing time by the patients were: Being away from home 68.8%, being too busy 58.9%, forgetting 49.0%, having too many medicines to take 32.6% and stigma attached to ARVs 28.9%. There was no significant difference between males and females based on timing of taking medications ($\chi2= 2.9412$, $p = 0.0861$). On the basis of keeping clinic appointments, all the respondents claimed to adhere to scheduled clinics. However, from hospital records, it was established that only 93.5% of the respondents kept clinic appointments. The most common reasons for poor adherence to clinic appointments were; Being away from home (50%), forgetting (50%), being too busy (50%), stigma (70%), feeling sick (80%) and changes in work routine (60%). (Talam, Gatongi, Rotich & Kimaiyo, 2008).

CHAPTER 3

BACKGROUND OF STUDY AREA

The health care facility at which this study was conducted is called Plateau State Specialist Hospital (PSSH). It is a secondary health care facility located in Plateau State, North Eastern region of Nigeria. This facility is supported by the AIDSRelief Consortium, an Implementing Partner (IP) under the President's Emergency Plan for AIDSRelief (PEPFAR) ART project supported with funds from the United States Government. The study was carried out amongst a cohort of treatment naive patients (aged 24-49) attending HIV care in this facility and who had been on First Line ARV medications in this same facility for at least 6 to 12 months. The study did not include adherence to Opportunistic Infection (OI) prophylactic medications.

MATERIALS AND METHODS

Materials: The study involved the use of a University of Maryland School of Medicine-Institute of Human Virology (UMSOM-IHV) validated survey questionnaire administered to a cohort of 50 patients identified in PSSH and who satisfy the criteria of being on ARVs in the facility for at least 6 to 12 months.

Survey Methodology: Sampling Design: The research is subject to a sample size of 50 which is considered suitable. Simple random sampling was utilised. This sample will be made from a cohort of patients on First Line ARVs for at least 6 to 12 months accessing HIV care at a Secondary Health Facility known as Plateau State Specialist Hospital in Jos, Plateau State of Nigeria. A simple random sample refers to a sampling procedure where the population elements are given equal chance of being selected or included in the sample.

Measurement Instrument: A well designed questionnaire validated by the University of Maryland School of Medicine-Institute of Human Virology termed Version 2008 was utilized.

Statistical Analysis and Packages:
SPSS was utilized in analyzing the data obtained from the study. .

LIMITATIONS

Limitations associated with the study process itself are:

1. The literacy level of the average patient in this part of Nigeria is vey low and there are about 30 different ethnic groups in this part of Nigeria which has led to difficulty in getting the patients to understand some of the questions. Some information is lost in the process of interpretation.

2. The response rate to some questions was low, which may have been due to a lack of understanding of the question or not being willing to disclose.

3. Some of the respondents may give false or half-true responses in order to give a good impression of their adherence level because they are under the false impression that there are either rewards for good adherence or punitive measures like refusing to provide them with ARVs in future is they do not adhere to their medications. This also has the potential of skewing the data obtained.

4. Since adherence in this study is based on oral reports and not electronic pillboxes known as Medical Events Monitoring (MEMS), there is no other objective way of verifying their level of adherence.

Limitations associated with the statistical software used to analyse the data (SPSS) are:

1. Data files cannot contain more than 50 variables

2. Data files cannot contain more than 1500 cases

3. SPSS add-on modules (such as regression models or advanced models cannot be used with the student version)

CHAPTER 4

RESEARCH FINDINGS

With regard to education level, 90% of participants responded to this question and a total of 16% of the respondents had University level education, 38% had Secondary School level education and 30% had Primary School level education. Only 6% of the respondents had below Primary school level education (Table 4). Therefore a total of 84% of the respondents indicated some level of education which means the average literacy level of these patients is relatively high. This explains the strong impact of a lower literacy level on the tendency for the respondents to miss taking their ARVs. Therefore literacy level ($\chi^2 = 15.40$, df =8, p = 0.05) is one of the factors that determine optimal adherence to ARVs.

In addition, the research study showed that at least 20% of all the respondents took alcohol either every day (4%), more than once a week (6%), once a week (6%) or once a month (4%) (Table 2). This study indicated that there was a relationship between a alcohol consumption on respondents' tendency to miss their ARV doses ($\chi^2 = 26.58$, df = 8, p = 0.001).

Moreover, the study showed that only 6% of the respondents reported some form of Substance Abuse (Table 3). Therefore, in this study, there was no correlation between Substance Abuse (apart from alcohol) on respondents' ability to take ARVs regularly because it did not lead to them missing their ART doses ($\chi^2 = 0.69$, df = 2, p = 0.71).

The effect of non-disclosure of HIV status by respondents to their sexual partners could not be determined because 64% of the respondents said the question was not applicable to them (Araoye, 2003).

Moreover, 98% of respondents agreed that they can live a normal life if they take their ARVs as prescribed by the doctor. This has led to our rejecting the Null Hypothesis that optimal adherence to ARVs has no significant effect on the quality of life. Rather, we are led to accept the hypothesis that optimal adherence to ARVs has significant effect on the quality of life of HIV positive patients.

As regards, mental illness or signs of mental ill health amongst the respondents, 4% always felt sad and hopeless while 66% sometimes felt sad and hopeless within the last one month (Table 6). Also, 2% of the respondents always wanted to be alone while 44% sometimes wanted to be alone (Table 7). But only 28% of the respondents lost interest in their daily activities within the last month (Table 8). Moreover, only 30% and 42 % of the respondents occasionally felt confused or thought life was too difficult to go on with (Tables 9 & 10). Therefore, the research showed that respondents feelings of sadness/hopelessness had no effect on their missing their ARTs (χ^2 = 3.20, df = 4, p = 0.52). All the other questions associated with mental illness showed no significant effect of mental symptoms or illness on the respondents' missing their ARTs (Tables 6, 7, 8, 9 & 10).

Table 1: Number of doses missed by respondents in the previous 1 week.

How many ART doses have you missed in the last week?	Frequency	Percentage
None	37	74.0
Once	4	8.0
Not applicable	9	18.0
Total	**50**	**100.0**

Table 2: Pattern of intake of alcoholic drinks amongst respondents.

In the past month, how often have you had a drink containing alcohol?	Frequency	Percentage
Everyday	2	4.0
More than once a week	3	6.0
Once a week	3	6.0
Once this month	2	4.0
Never	0	0.0
No response	40	80.0
Total	**50**	**100.0**

Table 3: Pattern of Substance Abuse amongst respondents.

In the past month, how often have you used cocaine, marijuana, or other drug?	Frequency	Percentage
Everyday	3	6.0
More than once a week	0	0.0
Once a week	0	0.0
Once this month	0	0.0
Never	0	0.0
No response	47	94.0
Total	**50**	**100.0**

Table 4: Educational level of respondents.

What is your educational level	Frequency	Percentage
Primary	15	30.0
Secondary	19	38.0
University	8	16.0
Below primary school	3	6.0
Not applicable	5	10.0
Total	**50**	**100.0**

Table 5: Respondents participation in an HIV/ART Structured treatment preparation session.

Did you participate in an HIV/ART structured treatment preparation session	Frequency	Percentage
Yes	49	98.0
No	0	0.0
Not applicable	1	2.0
Total	**50**	**100.0**

Table 6: Respondents tendency to feel sad and hopeless.

In the past month, have you had persistent feelings of sadness/hopelessness that you just can't control	Frequency	Percentage
Always	2	4.0
Sometimes	33	66.0
Never	0	0.0
No response	15	30.0
Total	**50**	**100.0**

Table 7: Respondents tendency to feel the need to be left alone.

How often do you feel the need to be alone?	Frequency	Percentage
Always	1	2.0
Sometimes	22	44.0
Never	0	0.0
No response	25	50.0
Not applicable	2	4.0
Total	**50**	**100.0**

Table 8: Respondents tendency to being apathetic

In the last month; have you lost interest in what used to give you pleasure?	Frequency	Percentage
Always	0	0.0
Sometimes	14	28.0
Never	0	0.0
No response	36	72.0
Total	**50**	**100.0**

Table 9: Respondents tendency to feel confused.

In the past month, how often have you felt confused or not yourself	Frequency	Percentage
Always	1	2.0
Sometimes	15	30.0
Never	0	0.0
No response	30	60.0
Not applicable	4	8.0
Total	**50**	**100.0**

Table 10: Respondents tendency to feel despondent

How often do you feel that life is too difficult for you to go on?	Frequency	Percentage
Always	0	0.0
Sometimes	21	42.0
Never	0	0.0
No response	29	58.0
Total	**50**	**100.0**

CHAPTER 5

<u>DISCUSSION</u>

The main aim of the study is to identify factors that determine optimal adherence to anti-retroviral medications with a view to using these findings to improve upon the quality of care amongst PLWHAs. From the study certain factors have been identified that have an effect on optimal adherence. A very important factor that impacts adherence as determined from the study is respondents' literacy level. For instance, the study showed that respondents with Primary and Secondary School education were 30% and 38% respectively. But respondents with University and below primary education accounted for 16% and 6% of the respondents. However, the effect of literacy on the tendency for the respondents to miss doses of their ARVs was found to be statistically significant as shown in the results above ($p < 0.05$). Therefore, the results show that the higher the level of education of respondents, the less the chance of them missing their ART doses.

This finding is very significant because it differs from findings in resource-rich settings where most previous adherence studies were carried out. One of such studies in a resource-rich setting showed that educational status, gender, insurance status, and HIV risk factors are generally not associated with adherence behavior (Volberding, Sande, Lange, Green & Gallant, 2008). The findings from this study therefore, shows a difference in adherence in resource-poor settings like Nigeria compared to adherence in resource-rich settings like Europe and America. This difference in adherence between resource-limited and resource-rich settings is further highlighted by the fact that several groups have voiced concerns about the ability of patients in resource-limited settings to maintain the high level of adherence required to obtain adequate viral suppression and hence prevent the emergence of resistant strains of the virus (Volberding, Sande, Lange, Green & Gallant).

The findings from this study pre-suppose this concern of non-adherence to ARVs in resource-limited settings to be unfounded. In addition, patients' knowledge of adherence (a function of the patients' literacy level) has a strong bearing on adherence. "Patients must understand why they have to adhere to their ART. This is a key point. It is not enough to say "…*you must take your*

ARVs every day, without missing!...you cannot miss any doses no matter what!" Patients should have comprehensive knowledge (a function of literacy) about adherence (Etienne & Amoroso, undated). Therefore, it becomes obvious that adherence to ARVs in regions of Africa where the literacy level is very low will become very challenging indeed. In a study conducted in Southwest Ethiopia, the researchers also noted that several studies have documented that inadequate knowledge (which may be a function of literacy as seen in this study) about HIV disease and treatment effectiveness present important barriers to ART adherence (Amberbir,Woldemichael, Getachew, Girma & Deribe, 2008).

In addition, this study found a strong effect of alcohol consumption on respondents' tendency to miss their ARV doses ($p = 0.001$). This finding is in keeping with the findings documented by Volberding et al. who identified alcohol as one of the barriers to adherence (Volberding, Sande, Lange, Green & Gallant, 2008). The consumption of alcohol by PLWHAs has led to what can be termed a 'vicious cycle of doom'. This is because, the more alcohol is consumed, the lesser the patients' adherence and the more he/she is likely to engage is risky sexual activities while also exposing him/herself to liver toxicity that may further compromise the ability of the already overwhelmed liver to adequately metabolize the ARVs. In fact, beliefs that alcohol facilitates or enhances sexual intercourse contribute towards consumption before or during sexual intercourse, according to a WHO study (www.forut.no, 2008). Alcohol is commonly used as a disinhibitor, a sex facilitator, a symbol of masculinity, and a means of relaxation, recreation, socializing and improving communication skills (e.g. in Mexico and Romania). Alcoholic beverages are also used as a facilitator in approaching the opposite sex (Endal, 2008). Very importantly, "there is now some documentation available on the impact of alcohol on adherence to ART medication. At a conference in Toronto, Canada in 2006 the results of a computer simulation were presented. In this study alcohol consumption was shown to have a significant impact on the survival of HIV infected persons, ranging from one year and up to 6.4 years. Hazardous drinking decreased overall survival by more than 3 years, if the frequency of consumption was once a week or higher, and by 6.4 years with daily consumption. Moderate drinking decreased survival more than one year if consumption occurred once a week or more often, and by 3.3 years with daily consumption (http://add-resources.org, 2008). This means alcohol consumption had an impact on the quality of life which by extension also affects adherence to ARVs.

Another very important finding from the study is the validation of the fact that indeed, adherence has a significant effect on the quality of life of HIV positive patients. From the study, 98% of the respondents agreed that they can live a normal life if they take their ARVs as prescribed by the doctor. This important finding has led to our rejecting the Null hypothesis that optimal adherence to ARVs has no significant effect on the quality of life of HIV positive patients. Rather, we are led to accept the hypothesis that optimal adherence to ARVs has significant effect on the quality of life of HIV positive patients.

In a study published in IAPAC monthly-Vol. 9. No. 7, quality of life was said to have increased significantly in patients taking ARVs (Fumaz & Clotet, 2003). The same study also stated as part of its conclusion; that "undoubtedly, quality of life may benefit from a simplified ART regimen (as seen in resource-limited settings like Jos in Nigeria). A study carried out in Tanzania revealed findings which suggest that improved quality of life due to adherence to ARVs was perceived by family and community members to have a wider impact on the ability of HIV positive persons to care for immediate members of family (such as children and dependants) (Ezekiel, Talle, Juma, Mnyika & Klepp, 2008). This shows the importance of optimal adherence to ARVs not just to the patient but to the family and community at large because the more improved his/her quality of life is from adhering to treatment, the healthier he/she will ultimately be which will make him or her more useful to self, family and society as well.

The effect of non-disclosure on optimal adherence could not be determined from the study due to the fact that most of the respondents (64%) did not answer the question. Therefore, there are no inferences that can be made from the study from this data. In addition, the respondents' mental state did not have any effect on optimal adherence as seen from the study results. This might not be unconnected to how the questions in the survey was presented and how the respondent understood the question and may have been a function of the capacity or ability of the translator to adequately pass on the message in the questionnaire. (Plateau State has about 30 different dialects).

In addition, it would have been very helpful to the study if respondents CD4 count and Viral Load could be estimated at least twice in an interval of at least 6 months to see how well their

adherence level correlates to the immunological, virological and clinical status at subsequent follow up visits. This will further validate the effectiveness of whatever adherence intervention they were engaged in.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

The first hypothesis of the study is that adherence to ARVs has significant effect on the quality of life of HIV positive patients. The results of the study indicate that indeed, adherence to ARVs has significant effect on the quality of life of HIV positive patients.

The second hypothesis of the study is that distance from health care facility, convenience, alcoholism, family support, non-disclosure of HIV status, ARV toxicity and side effects and substance abuse affect optimal adherence to ARVs. The results from the study identified literacy to have a significant effect on optimal adherence to anti-retroviral medications which is a very important finding in this part of Nigeria, sub-Saharan Africa where the literacy level is usually very low. In addition, the results of the study also indicate that alcoholism has a very significant effect on adherence to ARVs. The study however, could not indicate or validate the effect of distance from health care facility, convenience, family support, non-disclosure of HIV status, ARV toxicity and side effects and substance abuse on optimal adherence to ARVs. This might not be unconnected to the fact that the response rate in these specific areas of information in the survey questionnaire was low.

However, there is the need to ensure that patients adhere to their medications because that is the cornerstone of success in anti-retroviral therapy. Therefore, specific recommendations to improve optimal adherence to ARVs include the following:

i. There is a high prevalence of the excessive consumption of alcoholic beverages amongst tribes in this area which has led to patients being unable to adhere to their medications as a result of this dangerous habit. It is therefore, important to amend the treatment preparation process to include specific strategies to reduce the tendency for patients to engage or re-engage themselves in excessive alcohol consumption after diagnosis. Strategies to help reduce their alcohol seeking tendency could include but is not limited to spiritual counseling, avoiding peer pressure especially for youths and young adults and regular attendance at clinics and support group activities where issues like how to

live positively without recourse to alcoholism are regularly addressed. Experience sharing by other PLWHAs who have struggled with and overcome alcoholism during support group meetings also help in no small way to encourage patients to withdraw from excessive alcohol consumption.

ii.   The importance of the community adherence support mechanisms cannot be over-emphasized. Especially in this part of the world where the community actually starts from one's extended family system. Therefore, it will greatly assist patients' adherence if church groups, age groups and other peer groups are trained on avoiding stigma and embracing how to adequately support PLWHAs. This is because although the potential for adherence support abounds in the communities, stigma and discrimination against PLWHAs has greatly hampered the use of this great potential.

iii.   The role of the media in fostering adherence to ARVs has not been adequately explored. This area needs to be empowered and enabled in terms of government-sponsored programs on Television, Radio, News Media and the use of Information, Education and Communication (IEC) materials that will be produced and translated into local dialects that will disseminate adherence messages which will help to improve adherence.

iv.   Poverty and malnutrition are very rampant in this part of Africa and there is no way a hungry patient can adhere to the strict adherence requirements of ART. Therefore, special schemes to empower PLWHAs such as the so-called Meaningful Involvement of People with AIDS (MIPA) need to be strengthened by setting up schemes that will train PLWHAs on Income Generating Activities (IGAs) like Soap-making, Hair-Dressing, Sewing and other means of supporting themselves. Funding for this activity can either come from government or from private donations in Churches, Mosques and other community-based groups like age-groups etc. Foreign donor funds like PEPFAR and other funding streams can also be tapped into in funding this activity.

v.   The study identified low literacy from lack of education as an important contributor to the inability of the patients to achieve optimal adherence to ARVs. Therefore, all treatment adherence methods in this facility and indeed, other facilities supported by the AIDSRelief PEPFAR program, will need to restructure their adherence and treatment preparation protocols to ensure that non-literate patients about to start therapy are given a

special package of treatment education and preparation that might involve more practical ways of passing the message of adherence to ART. This will include using the local dialect of the patient to pass across the message on adherence and using pictograms or drawings to show the effect on non-adherence to ARVs on the patients' immune system along with diagrams of how the virus develops resistance to the ARVs and then over-powers the body's already weak immune system.

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