FACTORS AFFECTING ADHERENCE TO ANTI-RETROVIRAL DRUGS (ARVs) AMONG HIV/AIDS PATIENTS ATTENDING KAWOLO HOSPITAL HIV ART CLINIC:

BUIKWE DISTRICT UGANDA

BY

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DECLARATION

I Isabirye Isa a student of the school of health sciences, Kampala International University western campus declare that this research report is my personnel original work and has not been a duplicate of anybody's work.

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CHAPTER ONE: INTRODUCTION

1.0 Introduction

This study was set to examine factors affecting adherence to ARVs among HIV/AIDS patients attending Kawolo Hospital HIV Clinic Buikwe District. Adherence is an indication of the degree to which patients follow advice regarding the long term treatment (Hsu, 2005).Adherence involves a mutual decision making process between the patient and the health care provider. In adherence, therefore, the patient plays an active role in the decision and commitment to follow the prescribed regimen (Population Council et al 2004).

This chapter therefore, presents the research background, statement of the problem, study purpose, objectives of the study, stated hypothesis, study scope and justification of this study as well as definition of key concepts.

1.1 Background of the Study

The impact of HIV **worldwide** will be felt for decades to come. Promising developments have been seen in recent years in global efforts to address the HIV/AIDS epidemic, including increased access to effective treatment and prevention programmes (UNAIDS/WHO, 2006). In low and middle income countries 3 million people were receiving ARV treatment by end of 2007 (UNAIDS/WHO, 2007, 2008).

Sub-Saharan Africa remained the most affected region in the global AIDS epidemic (WHO, 2005, 2006, 2007). About 2.1 million people in Sub-Saharan Africa were receiving ART by end of 2007 (UNAIDS/WHO, 2008

In developing countries like Uganda, HIV/AIDS has become the most devastating disease humankind has ever faced (Uganda Aids Commission, 2003). **Uganda** had over 100,000 people accessing ARVs (MOH-2008) at no cost out of which 5,741 patients get treatment services from Infectious Diseases Clinic (IDC) Kampala.

 Poor adherence prevents one from obtaining the full benefits from one's anti-HIV medication (Academic Alliance, 2005; Boden D et al 1999; Hedit FM et al 1998; Little SJ et al 1999; Little SJ et al 2001).

The development of resistance to therapies is another serious public health issue related to poor adherence, among other factors.

Good adherence to treatment with antiretroviral agents might have an important impact on public health by breaking the transmission of the virus because of the lower viral load found in highly adherent patients.

The success of adherence depends on continuous research to investigate the factors that influence adherence and implementation of evidence based plans to deal with adherence issues

1.2 Problem Statement

Adherence is hard for everyone and long term treatments present the most difficult challenges, Despite several researches and subsequent adherence improvement strategies implemented in both formal and informal HIV/AIDs care systems, there continues to be a tendency to rely on and generalize researched factors as representative causes of good or poor adherence in HIV/AIDs treatment and care systems and no attention has however been paid to investigate the uniqueness of adherence factors that are particular and critical to individual HIV/AIDS care and treatment institutions. This study is set to examine a range of factors and their influence on patients' adherence among clients attending ART clinic under Kawolo Hospital in Uganda in particular.

1.3 General objective.

The aim of this study was to examine a range of factors and their influence on patients' adherence to ARVS among clients attending HIV/ART clinic under Kawolo hospital in Uganda in particular so as to plan to minimize the emergence of viral resistance and prevent therapeutic failure especially in resource limited setting of the rural Uganda as is the case for Buikwe district.

1.4 Specific Objectives.

This study was guided by three set objectives;

1. To examine the patient related factors that influence patients' adherence among attending clients at ART clinic in Kawolo Hospital Buikwe district.

2. To establish the prescription related factors affecting adherence as reflected from patient's records and views of health staffs at ART clinic of Kawolo hospital Buikwe district.

3. To elicit the outcomes of poor adherence and attitudes of the affected clients among HIV/AIDS patients attending ART clinic at Kawolo Hospital Buikwe district.

1.5 The hypothesis.

There are specific factors that lead to poor adherence to ARV medication unique only clients attending HIV ART clinic at Kawolo Hospital Buikwe district that can be identified and improved on.

1.6 The Scope.

This research was carried out in a period of two months at Kawolo Hospital HIV/ART clinic whose clients come from a wider catchment area of both Mukono and Buikwe districts and the average population is about five hundred clients /patients per month in that particular clinic.

1.7 Conceptual Framework

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┌─────────────────────────────────────────┐
│ Communication to HIV/AIDs Patients       │
│                                          │
│     -   Guidance                         │
│     -   Trust and care                   │
│     -   Dialogues on ARVs                │
└─────────────────────────────────────────┘

┌──────────────────────┐    ┌──────────────────────┐    ┌──────────────────────────┐
│ Patients' Behavior   │    │ **Range of factors** │    │       Adherence          │
│                      │    │                      │    │                          │
│   -  Beliefs         │    │ Patient related      │    │   -  Relative adherence  │
│   -  Attitudes       │    │                      │    │   -  Adequate adherence  │
│   -  Life styles     │    │ Prescription related │    │   -  Poor Adherence      │
│   -  Culture         │    │                      │    │                          │
│                      │    │ Outcomes of adherence│    │                          │
└──────────────────────┘    └──────────────────────┘    └──────────────────────────┘

                            ┌──────────────────────────┐
                            │ Side Effects / prescriptions │
                            │                          │
                            │     -   Vomiting         │
                            │     -   Nausea           │
                            │     -   Neuropathy       │
                            │     -   Insomnia         │
                            └──────────────────────────┘
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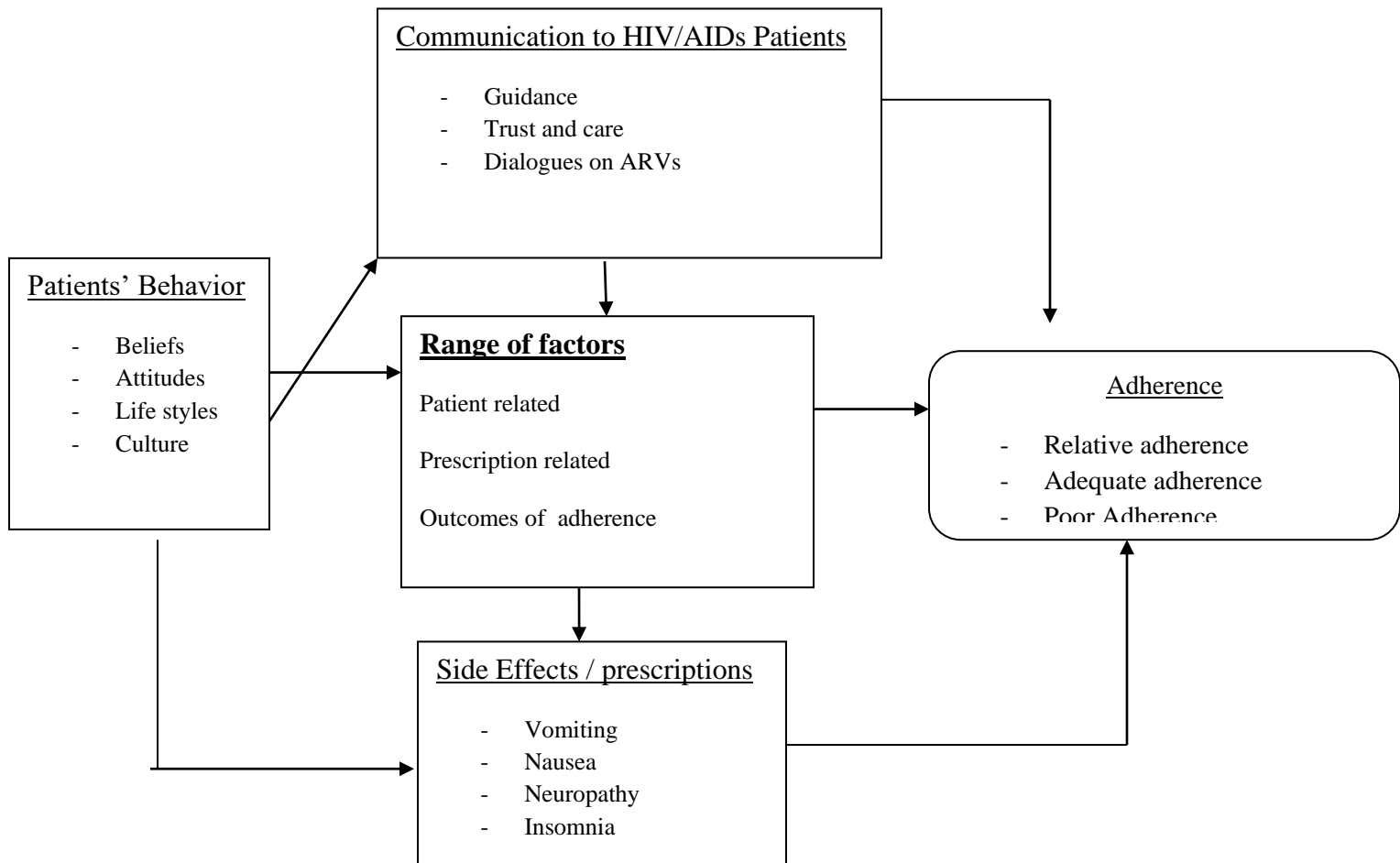
1.8 Justification of the Study

Long-term adherence interventions are needed for durable effect in any particular care center and they preferably need evidence based set plan of care.

This study was hence to provide information on a range of adherence factors and level of adherence that shall be a very useful supplement to other scholars who will conduct related studies in Kawolo Hospital Buikwe district Uganda.

Kawolo Hospital HIV/ART clinic managers shall derive information for planning focused interventions and effective strategies directed at maximizing long-term patient adherence for successful treatment and care of HIV/ AIDS clients particularly attending Kawolo Hospital HIV/ART clinic in Buikwe district Uganda.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter provides for the review of related literature regarding adherence, factors affecting patients' adherence to ARVs. This chapter reviews related findings on characteristics of drugs (ARVs) that influence patients' adherence, the relationship between patient adherence and characteristics of ARV drugs, poor adherence and attitudes of the affected clients.

Adherence to antiretroviral therapy (ART) is well recognized to be an essential component of individual and programmatic treatment success. Higher levels of adherence are associated with improved virological and clinical outcome (Paterson et al., 2000; Orell et al., 2003). Near perfect pill taking (values exceeding 95%) are desirable in order to maximize the benefits of ART (Paterson et al., 2000; Gross et al., 2001). This means taking the correct dose of drugs at the right times and observing any dietary restrictions (Paterson et al., 2000; Carter, 2005). Anything less than this leads rapidly to the development of viral resistance and hence to much earlier treatment failure (Paterson et al., 2000).

2.1 Understanding Adherence

To achieve effective treatment and realize the benefits of treatment, strict adherence to treatment instructions are very critical. Sticking to the treatment instructions for a long-term illness poses a great challenge to the patients (WHO, 2004). Just having medicine available cannot solve the HIV and AIDS problems. Worldwide, regardless of the illness or treatment many people do not take their medications correctly. A significant proportion of all hospital admissions are due to drug non-adherence. In a survey in U.S.A by Stone (2000), 21 % of HIV/AIDS patients who were on ARV drugs had missed a dose in 24 hours while 34 % had skipped a dose in 3 days. In Uganda, adherence of patients on ARVs remains very low as attributed to several factors but other studies have not explored the patient related characteristics , attitudes and to understand the context of drugs. There is need to further explore how patients react towards the drug characteristics.

Scholars have also investigated characteristics of Adherence. According to Hill et- atl 2003:521), It includes different behavioral/patterns and these include; taking medication very rarely (once in a week/ month), alternating between long periods of taking or not taking medication, skipping entire days of medication, skipping doses of medication, skipping one type of medication, taking the medication for several hours late, no sticking to eating/ drinking requirements of medication, adhering to a purposely modified regimen, adhering to unknowingly incorrect regimen. A single patient may alternate between different main and/or behavior patterns or display it simultaneously; one patient for example may change the number of daily dozes due to the belief that he/she is healthier and does not need much medication while another decreases number of daily doses because there is never time in the middle of the day to take medication.

Several factors are associated with adherence to drugs as described by Wagnar (2000:602-605) & Johnson, Catz , Remien); Demographic data, Psychosocial data including (depression), social support, attitudes, and beliefs towards perceived treatment efficacy and self-efficacy. The ability to integrate the medication administering regimen into daily routine, treatment characteristics like side effects and the amount of pills to be taken daily, patient-doctor relationship. For the patient related factors include a patients' perception of the benefits and side effects of particular treatment as well as knowledge regarding diagnosis, emotional support provided by health care team, forgetfulness, psychiatric conditions such as depression and social economic factors.

Regimen- related factors refer to the number of the drugs, frequency of dozens, ease of taking medication and length of treatment,(Tsasis 2001). While several factors have been explored, it is crucial to try to establish the relationship between drugs (ARVs) characteristics and patients' adherence; this is intended to close the gap existing with currents studies regarding patients' adherence.

Patient adherence levels vary between 50% for depression to 63% for enlarged prostate. According to interviewees, on average adherence levels drop over the course of the patient journey from 69% of patients filling their first prescription to 43% continuing their treatment as prescribed after 6 months. The vast majority of pharmaceutical, pharmacy and payer executives explain low adherence levels by pointing to patient related factors, such as poor knowledge of the disease, inadequate perceptions of the need for treatment and forgetfulness. Other factors, such as the route of administration of therapy or side effects, are often mentioned too.

Divergences appear with regard to the impact of treatment costs or socio-demographic factors: pharmacists dismiss the first – both manufacturers and pharmacists dismiss the second, Global Research Report by Capgemini Consulting (2009) vision and reality 9th edition.

According to Miller & Hays, (2000) and Johnson et-atl, (2003), a patient's ability to adhere to a specific medication regimen is greatly induced by individual and his/her natural environment for this reason, the importance of multi-faceted and individual tailoring in contrast with single approaches cannot be traced enough. Adherence intervention should address specific issues that hinder patients' to achieve or maintain adequate adherence; it is on this matter therefore, that poor adherence, attitudes is not fully established and this study seek to address this matter among the HIV patients.

HIV and AIDS treatment in Africa

At the end of 2005 only 1.3 million people in low and middle-income countries were receiving ARV medication. This was just 40% of the target. Across sub-Saharan Africa 1.34 million (28% of those in need) were on ARV treatment out of an estimated 4.7 million who needed it (UNAIDS/WHO, 2006, 2007).

Uganda ran one of the first pilot ARV programmes in Africa. It begun in 1998 and aimed to see how an ARV programme could be set up and run in resource poor country. The 399 patients involved were responsible for paying for their treatment and bought their drugs at negotiated reduced prices. At the end of the two-year pilot, patients reported good adherence to treatment and biological and immunological response to ART were similar to those found in western countries (Byakika et al., 2005; UNAIDS/WHO, 2005). Uganda exceeded a government target of 60,000 treatments by the end of 2005. The number had risen to 96,000 by the end of 2006, which was around 41% of those in need (UNAIDS/WHO, 2006).

Malawi has an adult HIV prevalence rate of 14.1%, which translates to 940,000 people infected. As of June 2004, only 3,760 people were reported to be receiving the drugs (UNAIDS/WHO, 2004). The government later set a target of 50,000 people on treatment by the end of 2005, which was less than the 3 by 5 goal of 65,000. Having missed both of these targets (only reaching 33,000) by the end of 2005, Malawi set another goal of 80,000 by June 2006. In the event it took

another six months to reach 81,000 people on treatment, which was 41% those in need (UNAIDS/WHO, 2006).

The case for access of ARVs in South Africa has been the most high profile of all African countries. Data from the UNAIDS/WHO May 2006 report indicated that 5.5 million people were living with HIV at the end of 2005, which gives an adult prevalence rate of 18.8%. This means that South Africa has a high HIV prevalence than any other country in the world. In December 2004, the WHO estimated that 42,000-67,000 South Africans were receiving treatment. This figure rose to 178,000-235,000 by the end of 2005, 21% of the 983,000 people in need. This means that, despite being Africa's richest country, South Africa fell along way short of its 3 by 5 target. At the end of 2006 the number receiving treatment had grown to 325,000 or 33% of those in need, which is slightly above the average for Sub-Saharan Africa (UNAIDS/WHO, 2006, 2007)

2.2 Drug Characteristics (ARVs) and Side Effects

These are problems that occur when treatment goes beyond the desired effect, or problems that occur in addition to the desired therapeutic effect. Side effects are clearly a concern for patients taking antiretroviral drugs. In some cases side effects are insurmountable, and discontinuation or a change in medication is necessary, (Frank 1997; Chesney et al. 2000). Anticipatory fear or actual occurrence of side effects is a significant contributor to adherence in HIV treatment. Clinicians must be skilled at providing clients with information about possible side effects and approaches to dealing with them in advance of their occurrence (Dunbar-Jacobs 1997).

A big percentage of 79.7% had experienced some side effects at one time or the other while 16.9% had not experienced any side effects. Side-effects have also been consistently associated with decreased adherence and patients who experience more than two aversive reactions are less likely to continue with their treatment (MoH, 2003). However, side effects have been known to cause patients to request for regimen change or discontinuation of medication (Wenger et al. 1999). Whether real or perceived, side-effects account for more regimen changes than does

treatment failure (Catz et al. 2000; Stone et al. 1998; Lerner, Gulick , Dubler 1998). Only 3.5% did not respond to the question[1].

Headache, nausea, night mares, vomiting, loss of appetite, aches/pains, itching bodies, fevers, change in how one looks and sexual dysfunction ranked highest on the list of experienced side effects. Regarding how respondents have overcome side effects, counseling by health workers topped the list with 46.5%, this is also supported by the majority of the Key Informants who said that Pre-ART, on- ART and ongoing adherence counseling is done always, followed by friends and families 4.7%. Some patients became strong and expectant that they would get over the side effects as their friends had overcome, and this could have been as a result of interaction and sharing of experiences amongst themselves, therefore, counseling and sharing of experiences amongst patients should be encouraged, Kuteesa Damalie (2011).

There is need to study how the 24.4% of the respondents got over the side effects because they did not mention having done anything of the above. Some of the respondents did not indicate whether they had experienced any side effects at all (19.2%). It should however be noted that even when patients fully comprehend the consequences of non adherence to medications, adherence rates are suboptimal (Stephenson et al. 1993; Samot et al. 1993).

 Emotional affections while taking ARVs among HIV/AIDS Patients
It was found out that a big percentage of 68% felt good/better, this could be as a result of adhering to their medications which consequently improves on their lives. This could also be as a result of the positive beliefs regarding the efficiency of ARVs medication having a positive effect on their health (Mocroft et al. 2001. However, those who felt discriminated; pose a big challenge as it is widely believed that discrimination against PLWHAs has tremendously reduced worldwide, but this could also be as a result of hopelessness and negative feelings by the patients themselves about their lives (Paterson et al. 2000).

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[1] KUTEESA DAMALIE (2011), A study carried on ADHERENCE TO FREE ANTI-RETROVIRAL DRUGS , at Infectious   Disease Institute. This study intended to ascertain Patient's knowledge, attitudes and perceptions on the use of free ARVs.

However, for the expectancy mothers, according to World Health Organization and UNAIDS guidance modules on Antiretroviral treatment 6 vol 98 (2009) indicates that ARVS plays an important part in reducing mother-to-child transmission of HIV/AIDs but mean while it was proved true that MTCT is responsible for 5-10% of the total new infections each year in many developing countries, with more than 500,000 children. The introduction of ARVs for the prevention of MTCT has dramatically reduced the rates of transmission among non-breastfeeding mothers in many developed countries and continued improvement are being seen as more women enter pregnancy while on combination ARV therapy in developed countries.

2.3 Patient's Behavior and Adherence

There are many behaviors that constitute non- adherence. Simply not taking medication at the prescribed time is only one example of non-adherence to treatment (Malta et al 2004). Behavior change takes time, support and encouragement by the provider to the patient may require other support resources as well. It is well known that beliefs and values influence behavior particularly as it relates to adhering to complicated treatment regimens. (Dunbar-Jacobs 1997) Good communication between patient and provider about patient lifestyle and preferences can improve adherence by aiding in the selection of an ART regimen tailored to the patient's life style. (Wendo 2005).

In the study carried out by Patrick Oerah & John E Arute (2008), put the major reasons given for no adherence were non-availability of medications due to poor financial status and inadequate family support (15.9%), medication adverse effects (59.0%), lack of confidentiality (76.7%) and occupational factors (25.0%).

Dispensing of antiretroviral drugs in a common room to them in the pharmacy (as practices in the treatment center) was seen by 72.1% of the non-adherent patients as inappropriate and exposing them to discrimination (stigmatization) since patients entering the room were identifiable as HIV positive. Furthermore, some patients (11.4%) reported they were often unwilling to obtain permission from their working places to attend clinic regularly because they could not disclose their HIV status to their superiors.

Medication adverse effects and stock-out pill counts have not been included in our study because of the reliability of the measurements from previous studies. Short-term and long-term adverse

reactions (can be early and transient or evident with more prolonged use) have been identified with all of the available antiretroviral agents (Esch, 2001).

2.4 Poor Adherence and attitudes of Patients towards ARVs

"Patient adherence" is widely viewed as a combination of compliance and persistence. It is defined as the extent to which a patient follows a prescribed treatment regimen and includes taking a drug (as prescribed) and following physician advice. Understanding of the issue has evolved from the narrow scope of compliance, which places the entire responsibility upon passive patient, to a broader definition where adherence is a more collective responsibility between healthcare providers and patients who are active participants in their own care.

Despite this evolved understanding, in general the issue of poor adherence has not been given the priority it deserves. Consequently, in the past it has received insufficient direct, systematic or sustained intervention. Adherence to prescribed medications poses a tremendous challenge to the entire healthcare community. In fact, almost all chronic conditions face high rates of non-adherence and those with no visible symptoms, such as depression, have the lowest adherence rates[2].

The problem even extends to oral formulation chemotherapy drugs, where one would not expect to encounter patient adherence issues due to the seriousness of the condition. As much as 40% of cancer patients are no adherent. Increasingly, poor medication adherence is being recognized as a significant source of waste by the healthcare system and life sciences companies. Capgemini Consulting's survey revealed an average adherence rate of 69% for first filling of prescription, with a 40% drop in adherence from first filling of prescription to continuous refill after six months.

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[2] Thinking outside the pillbox: A system-wide approach to improving patient medication adherence for chronic diseases", New England Healthcare Institute (NEHI), July 2009

2.4.1 Misunderstandings about ARVs and confusion among HIV Patients

From the study carried in South Africa by Sumaya Mall (2008) showed that the people had a different picture and attitude on use of ARVs for example regarding its side effects. The first theme illustrated that the side effects of ARV therapy could result in patients feeling confused about their treatment. They may believe the side effects are actually an illness of their own.

'I visited a traditional healer because I felt I wasn't getting any better by using ARVs. I thought the ARVs were making me feel worse. The traditional healer that I visited gave me some medication. I vomited. I had diarrhea. I was eventually hospitalized at Somerset hospital because of all these complications. But I still don't know what can help my headaches.' (Male Patient, Du Noon).

There is also the possibility that patients may be confused by the symptoms of HIV/AIDS and believe that their illness is caused by a cultural duty. 'I am so confused. The Traditional Healer tells me I am sick because my ancestors are calling me to become a traditional healer. The clinic tells me I am sick because of a virus called the HI Virus. The traditional healer does not advise me to come to the clinic. Instead he advises me to drink Xhosa beer, slaughter goats and cows. When I feel better, I am not sure if the clinic is helping me or the bottle of traditional medicine that the traditional healer has given me…I told the traditional healer I was taking ARV drugs. I take the traditional drug regimen at the same time that I takes her ARV drugs. I know that my life has improved on ARV drugs but I still experience TB, rashes as well as anxiety. This is why I visit the traditional healer because of my anxiety and my confusion.' (Female Patient, Du Noon)[3].

From the about two illustration, is indication in some African countries, many HIV/AIDS victims continue to believe in various aspects regarding the cause, side effects and other

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[3] **Sumaya Mall (2008),** Attitudes of HIV Positive Patients In South Africa CENTRE FOR SOCIAL SCIENCE RESEARCH: Aids and Society Research Unit. CSSR Working Paper No.215, the paper explores the beliefs and attitudes people had about ARV visa vi the traditional practices.

chronic illness and this no doubt hampers the adherence level. Sometimes they believe the traditional healing makes them feel better as compared to the ARV drugs and this is a big misconception. This study is therefore set to investigate further into the attitudes towards the ARV drugs.

But on a good record, Sumaya Mall (2008) noted that Most of the patients in this group said they did not believe in traditional healing. As one patient explained, 'seeing a traditional healer was never an option for me. I went straight to a clinic when I found out I was HIV positive.' Another patient alluded more directly to her belief value system: 'I only believe in the medical doctor'.

There were more complex reasons for the choice of these patients not to access any form of traditional healing service. These included psychological issues (such as trust, fear, and religious belief and childhood experiences) as well as issues related more directly to treatment (the perceived incapacity of traditional healing to deal with HIV/AIDS, possible adverse drug interactions and lack of scientific evaluation of traditional medicine). It was clearly concluded that although there are patients who have never used a traditional healing service, there are others who have may visit a traditional healer during their initial phases of their HIV positive diagnosis. The patients who have ties with traditional healing practice themselves demonstrate particularly interesting healing strategies. They claim they do not use untested traditional treatment on HIV positive patients or to take this treatment themselves. They also claim they encourage clients to access VCT services at local clinics and in the event of an HIV positive diagnosis to adhere to ARV treatment,(Samaya Mall (2008).

CHAPTER THREE: METHODOLOGY

3.0 Introduction

This section describes the methods that were used in carrying out the research. The chapter looks at study area, study design, target and study populations, sampling techniques, research instruments, ethical considerations, data collection, data quality control, data management and analysis as explained:

3.1 Research Design

A cross-sectional study design was used. The study design provided information about the presence and strength of associations between variables, permitting the testing of hypothesis about such associations. Both primary and secondary data was collected. Primary data was collected through interviewing study participants, key informants (health care providers), and conducting focus group discussions and through observation. Secondary data was collected through reviewing medical records of the study participants after getting authority from health facilities' administrators and consent from study participants.

3.2 Study Area

This study was carried out in Kawolo Hospital Buikwe District. The hospital is situated in Lugazi town council Buikwe District, along the Kampala-Jinja Highway, approximately 50 kilometres (31 miles) by road, east of Kampala, Uganda's capital and largest city. Its location is approximately 23 kilometres (14 miles), by road, east of Mukono, the nearest large town, also along the highway between Kampala and Jinja The coordinates of the town are:00 23 00N, 32 52 27E. The average elevation of the Lugazi is about 1,204 meters (3,950 ft)

Kawolo Hospital, located on the Kampala-Jinja highway, has been operational since 1968.

3.3 Study Population

The study focused on AIDS patients taking ARV medications and attending ART clinic in Kawolo hospital Buikwe district Uganda.

	Kawolo HIV/AIDS Clinic
Heath Service providers	05
HIV/AIDS Patients	100
Total	105

Source: primary data

3.3.1 Inclusion and Exclusion Criteria of Target Population

The inclusions focused on HIV/ AIDS patients who had started taking ARV drugs within the last five years and were willing to participate in the study. The benchmark of adherence was set as at the day the patient started on ARV treatment because even missing one dose of ARV drugs in a week translates to only 92.8% adherence, which is sub optimal (Paterson et al, 2000). However, AIDS patients who had not started ART and those who did not have interest were not enrolled into this study

3.4 Sample Size

A sample of 110 respondents was used in the study. This was determined based on the Krejcie and Morgan table (1970), of determining sample size. See Annex 3 attached

Proportionate of randomly sample population

Kawolo Hopital **HIV/AIDS Clinic (Stratum)**	Estimated pop	Sample Size
HIV/AIDS patients on ARVs	140	100
Key informants (Health providers)	05	05
Total		**105**

Source: primary data

3.4.1 Sampling Techniques and Procedure

The researcher employed purposive and simple random sampling. Purposive sampling was used for selection of respondents by virtue of their experience and position like the Pharmacists, Doctors or other health care providers of Kawolo Hospital ART clinic. While Simple random sampling was used to give the respondents the same chances of being involved in the study, these included HIV/AIDS patients.

Category of the Respondents	Sample Size unit	Sampling technique to be used
Health providers (Doctors, Nurses, Pharmacists) *key Informants*	05	Purposive sampling
HIV/AIDs Patients	100	Random Sampling
Total	105	

3.5 Data Sources

3.5.1 Primary data

Primary data was collected from HIV/AIDS patients using self-administered questionnaires, interviews. Research Assistants were used to capture and record information throughout data collection time

3.5.1 Secondary data

The secondary data was obtained from records at Kawolo Hospital ART clinic.

3.6 Research Instruments

3.6.1 Questionnaire

Quantitative data was collected using structured questionnaire with both open and closed questions.

3.6.2 Interview guide

In addition key informant interviews were carried out among health care providers at Kawolo Hospital ART clinic. These may include Clinicians, Nurses, Pharmacists and Social Workers. The information generated was used to give detailed investigation regarding the statistical

findings of each study objectives, therefore, open-ended set of questions were prepared to aid the interview process while important information is noted.

3.7 Data Collection on Adherence

Researchers who have tried to measure adherence have realized that there is no gold Standard by which adherence can be quantified (Farmer, 1999). This study therefore took on two measurement tools.

Two- day self-report recall

Patients were asked how they took their medicines in the last two days. The two-day recall has the advantage of a short time-span, which means that memory of medicine intake is likely to be good. However patients may feel ashamed to report specific instances of non-adherence that occurred in the 48 hours prior to visiting the health facility, especially if they have to specify on the chart exactly when they failed to take a pill and then to explain why.

One-month self-report recall (10 cm long visual analogue scale)

ARV users shall be asked to indicate their adherence rate over the past month using a 10-centimeter long 'visual analogue' line. The beginning of the line indicated not taking the medications at all in the past month, while the end meant taking all of them as prescribed. The patient's mark was then measured using a 10 cm ruler and translated into percentages. In terms of desirability bias, the one-month visual analogue methods are likely to be better.

3.8 Validity   and Reliability of Research Instruments

A total of 10 questionnaires were pretested among the respondents randomly and 5 sample interviews to make sure that the tool are cleaned of question errors.

3.9 Data Management and Analysis

Data from the patients on ART (respondents) was sorted, coded, and entered into the computer using SPSS software version 17.0. Data was processed, presented using charts, graphs and frequency tables. Descriptive statistics such as mean, frequencies and percentages have been used to describe and summarize the data.

3.9.1 Ethical Considerations

This study was carried out in consideration of ethical standards including but not limited to the following key issues:

- Seeking permission to carry out the research was taken into consideration from the concerned authorities to include; the university, the management and staff of Kawolo hospital ART Clinic.

- Informed consent was sought from all the study participants in writing and for minors the consent was obtained from their parents or guardians and they also assented to that effect

- Confidentiality, anonymity and privacy were fully guaranteed.

CHAPTER FOUR

4.0 DATA ANALYSIS, INTERPRETATION AND PRESENTATION OF RESULTS

4.1 Introduction

The chapter provides for the data analysis, interpretation as well as presentation of study findings; the study focused on factors affecting adherence to anti-retroviral drugs (ARVS) among HIV/aids patients attending Kawolo Hospital HIV Art Clinic. This study was guided by the following key objectives: to examine the patient related factors that influence patients' adherence among attending clients , to establish the prescription related factors affecting adherence as reflected from patient's records and views of health staffs, to elicit the outcomes of poor adherence and attitudes of the affected clients among HIV/AIDS patients attending ART clinic

Socio- demographic data of respondents

		Freq	Percent
Gender	Male	20	20.0%
	Female	80	80.0%
Total		100	100.0%
Age	18-20 years	12	12.0%
	25-35 years	54	54.0%
	40-45 years	16	16.0%
	50 and above	18	18.0%
Total		100	100.0%
Level of education	No formal education	20	20.0%
	Primary	40	40.0%
	Secondary	40	40.0%
Total		100	100.0%
Marital Status	Single	6	6.0%

	Married	62	62.0%
	Widow	22	22.0%
	Divorced	10	10.0%
Total		100	100.0%
Employment Status	Unemployed	30	30.0%
	Self employed	70	70.0%
Total		100	100.0%

The biggest number of respondents were female aged between 25-30 years and were married which significantly reflect positive treatment supporter.

An illustration of Age distributions
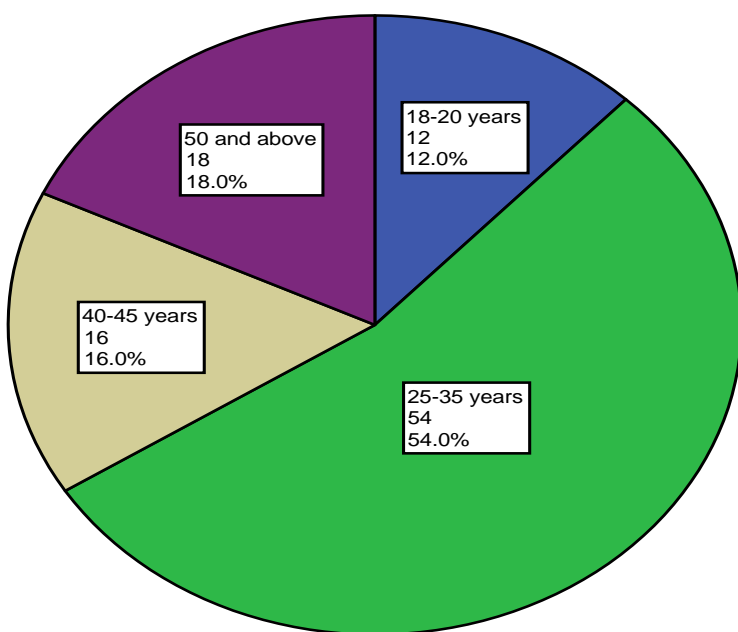
PATIENTS' BEHAVIOR AND PRESCRIPTIONS

		Freq	Percent
Have you heard about ARVs?	Yes	98	98.0%
	No	2	2.0%
Total		100	100.0%
Explain	ARVs are drugs given to HIV positive people	32	32.0%
	Are drugs used to treat HIV/AIDS	24	24.0%
	Are drugs given to lactating mothers	4	4.0%
	ARVs are drugs that boost CD4 count	22	22.0%
	Drugs that give someone a chance to live longer	12	12.0%
	Drugs that make HIV inactive in the body	6	6.0%
Total		100	100.0%
Do you take ARVs regularly as per prescriptions?	Yes	100	100.0%
Total		100	100.0%
Where do you access ARVs?	Kawolo HIV clinic	6	6.0%
	TASO Kawolo hospital	92	92.0%
	Private clinic in town	2	2.0%
Total		100	100.0%
What is the distance you take to the above mentioned health facility?	100 meters	34	34.0%

|			
	50km	42	42.0%
	200km	12	12.0%
	Don't know	12	12.0%
Total		100	100.0%
For how long have you been taking the ARVs?	Less than one month	12	12.0%
	3 Months	22	22.0%
	12 Months	26	26.0%
	24 months	40	40.0%
Total		**100**	**100.0%**
Drug related factors perceived by patients	Color of ARVs	16	16.0%
	Taste of drugs	54	54.0%
	Size of drug pills	24	24.0%
	Quantity/dosage	6	6.0%
Total		100	100.0%
Do you think the above mentioned drug factors affect you while on ARVs?	Yes	60	60.0%
	No	40	40.0%
Total		100	100.0%
If yes, how?	Vomiting	18	30.0%
	Nausea	40	66.7%
	Neuropathy	2	3.3%
Total		60	100.0%

COMMUNITY RELATED FACTORS FOR ADHERENCE

Table...How people in the community view HIV positive patients and reasons for the perceptions

| | | How do people in the community view HIV positive patients? | | | |
| | | Negative attitudes | | Positive attitudes | |
		Freq	Percent	Freq	Percent
Why?	They take a positive person as a dead one	14	50.0%		
	Face discrimination in the community	10	35.7%		
	Perceived to be responsible for the situation they are in	4	14.3%		
	Encourage us to go for treatment			24	33.3%
	Provide us with palliative care			18	25.0%
	Provide Hiv positive people with basic necessities			4	5.6%
	They do not discriminate			14	19.4%
	Encourage people to be tested for HIV			2	2.8%
	Due to sensitization			10	13.9%
Total		28	100.0%	72	100.0%

The table above reflects that the community views HIV/Aids patients realized that community member's call them dead people in a way that makes them feel stigmatized and hence affect some patients' adherence to ARV medications.

Rate of Adherence of HIV/AIDS patients on ARVs
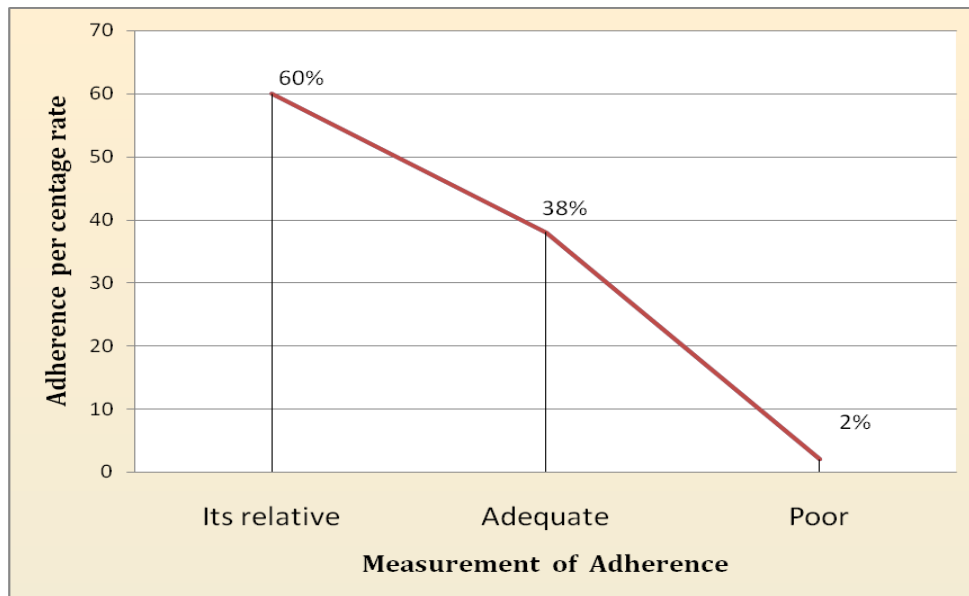
The graph indicate that majority of patients view their adherence as relative measures but this is almost ¾ (30%) who were adequately adherent to ARV medication.

Table illustrates   adherence of a HIV/AIDS patients   and reasons for the rate of adherence (prescription related factors)

| | | How do you rate your adherence on ARV drugs? | | | | | |
| | | Its relative | | Adequate | | Poor | |
		Freq	Percent	Freq	Percent	Freq	Percent
Reason for the answer	Takes the ARVs according to prescriptions	16	26.7%	14	36.8%		
	My condition is good/ has improved	16	26.7%	6	15.8%		
	Had enough health education about ARVs	8	13.3%				
	Takes the drugs on a daily basis	14	23.3%	16	42.1%		
	Misses doses for some days					2	100.0%
	Follow the directions of the prescription	6	10.0%	2	5.3%		
Total		60	100.0%	38	100.0%	2	100.0%

This table generally brings out reasons for the relative adherence rates other than the preferred adequate adherence. However, majority (42.1%) had adequate adherence because they take drugs on daily basis.

Factors that affect Adherence of HIV Positive Patients on ARVS (patient related)

		Freq	Percent
Have you heard about HIV?	Yes	100	100.0%
Total		100	100.0%
Have you heard about ARVS	Yes	100	100.0%
Total		100	100.0%
Difference between HIV and ARVs	HIV kills but ARVs reduce the multiplication of HIV virus	8	8.0%
	HIV is an STD while ARVs partly treat HIV	6	6.0%
	HIV attacks the immunity but ARVs raise it	10	10.0%
	HIV is a virus while ARVs are drugs that treat HIV	76	76.0%
Total		**100**	**100.0%**

PATIENT RELATED FACTORS FOR ADHERENCE

Table illustrates   factors affecting patients on ARVs

		Freq	Percent
Other factors that affect you as an HIV positive patient on ARVs	Nutrition	34	39.5%
	Limited income to buy other supportive drugs when sick	24	27.9%
	Limited awareness on ARVs	2	2.3%
	Substance abuse (behavior)	24	27.9%
	Availability of medicine	2	2.3%
Total		**86**	**100.0%**

The above table explains cure factors that are patient related and greatly affects patients' adherence like lack of food and subsistence abuse.

The myth conceptions on ARVs among HIV/AIDS patients (community related factors)

		Freq	Percent
Do you know any myth or misconception on ARVs	Yes	50	50.0%
	No	50	50.0%
Total		100	100.0%
myth1	ARVs cure HIV	4	8.0%
	ARVs lead to death	36	72.0%
	Makes someone sexually inept	2	4.0%
	Worsens someone's health	2	4.0%
	ARVs make one grow fat	4	8.0%
	ARVs make the body weak	2	4.0%
Total		50	100.0%

myth2	ARVs cure HIV	2	16.7%
	Makes someone sexually inept	4	33.3%
	Worsens someone's health	4	33.3%
	ARVs make the body weak	2	16.7%
Total		12	100.0%
myth3	ARVs make one grow fat	2	100.0%
Total		2	100.0%

Source: primary data

The findings indicate that the patients' views on a range of misconceptions to which 50% of the respondents are un aware of a strong misconception that ARVs lead to death of patients taking them which was highly reported (72%).

Challenges faced by HIV /AIDS Patients in accessing ARV drugs

		Freq	Percent
Challenges have you faced as an AIDS patient while getting Anti-Retroviral treatment from Kawolo Hospital HIV/ AIDS Clinic?	Long distance to the health facilities	10	31.3%
	Congestion at the health facility	8	25.0%
	Insensitive treatment by health care practitioners	2	6.3%
	Long waiting time	2	6.3%
	Transport to the health facilities	10	31.3%

Fig…: Challenges   faced by HIV/AIDS   patient while getting Anti-Retroviral treatment from Kawolo Hospital HIV/ AIDS Clinic
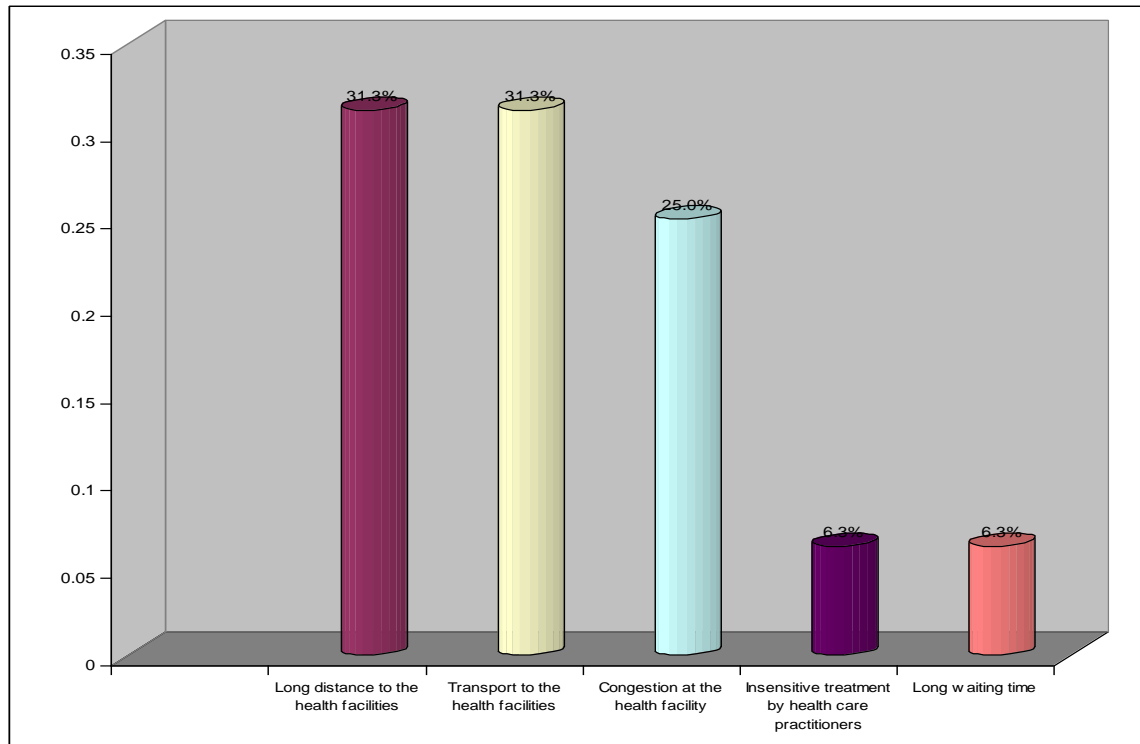
The most suggested proposals for improving access to ARVs were testing for HIV and taking resources nearer to their communities.

Fig…: Ways in which access to ARVs and adherence can be improved
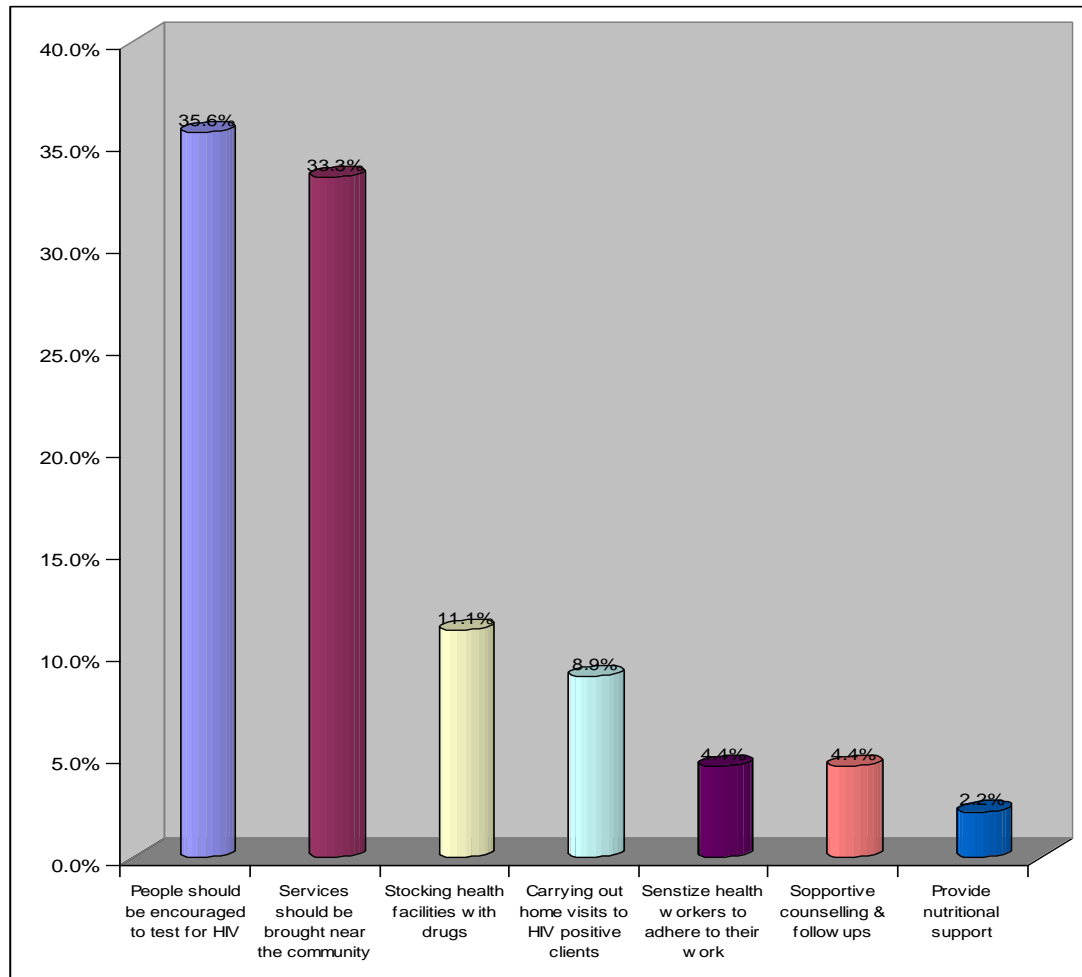
CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS AND RECOMMENDATIONS

Introduction

This chapter discusses the study findings, conclusions and recommendations.

5.1.0 DISCUSSION

5.1.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

The majority of the respondents were female (80%) and with largely above 25 years. This picture is a true reflection of a high female to male ratio of HIV infected persons in Uganda

Many of these respondents were married as represented in the summaries (62.0%) but still the single and divorced were a significant number and this truly gives the varied picture of socio economic challenges that these patients face especially in adherence to ARV medications.

The majority of respondents had ever attended a formal education and only 10% had never attended any formal education and because the patient key involvement in adherence following intensive and continuous counseling plays a big role to the success rates seen in terms of understanding and following instructions to take medications.

5.1.0 DISCUSSIONS

5.1.1 PATIENT RELATED FACTORS FOR ADHERENCE

About 50% of the respondents were aware of misconceptions attached to ARVs and that means that those who know the wrong things can easily reject to follow but the other 50% of the patients can easily be convinced to abandon ARVs should people with misconception messages approach them

Access to ARVs in terms of long distances and lack of transport to the moderately congested ART clinic were reported by the majority of respondents as major stubling blocks to their programmes.

Lack of nutritional support was the least reported hindrance to a few individual patients on ARV medication.

It is a potential risk for non adherence that cannot be solved with financial empowerment or food hand outs but rather taking services nearer to the communities.

About 20% of the respondents sighted substance abuse especially alcohol while on ARV medication. Substance abuse does not only predispose to non adherence but cause a risk for un wanted toxic drug interactions.

5.1.2 PRESCRIPTION RELATED FACTORS FOR ADHERENCE

Although about 50% of respondents said that they felt they were taking their medications as per prescription,26% clearly expressed a view that they were not adequately educated on ARV medication before starting to take them which is a potential risk to block adherence and may reflect a weakness in the system used or particular staff competencies

24% of the respondents reported pill burden in terms of large quantity dispensed to them but 50 % of the respondents reported the un palatable taste of medication that particularly transformed into nausea to about 66.7% of the respondents and a few(30%) real vomit after taking medication Since about 70% of the respondents had just taken ARV medications for a period of 2-12 months, its likely that such a group will report these earliest and inevitable side effects

It is also reported that nausea and vomiting are always present in ARV medication and tend to go away sooner. This finding is therefore common and carries no significant bearing with in a period of less than one year on medication

5.1.3 ATTITUDES OF AFFECTED CLIENTS ON ARVS

On the whole, a few clients (20%) in the ART clinic were found not to be optimally adherent to their ARV medication

These respondents reflected an attitude that quickly shifts blame to poverty and side effects of drugs other than personal failure indecision and active commitment.

A significant percentage of these respondents were single and divorced which is a key indicator of the difficulties with getting a close and committed home treatment supporter

The outcomes of poor adherence begin with individuals but in the long run become a public health problem in the fight against HIV/AIDS.

5.2 CONCLUSIONS

Patient related / community related factors are more likely to influence adherence to ARVs than prescription related factors and hence the patient should be the central target in the strategies to promote good adherence

5.3 RECOMENDATIONS

1. Adequate and continuous patient education and ongoing quality adherence counseling is a prerequisite to promote and sustain good adherence practices and hence a way to minimize consequences of poor adherence to ARVs.

2. Adequate staffing with relevant and trained health personnel to provide ongoing support to patients   whose decision and commitment is central to good adherence to ARVs.

3. The government should emphasize and ensure a continuous stocking of ARVs at treatment centers and also work out plans to scale up access to these medications through outreach services nearer to the communities.

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RESEARCH WORK PLAN

Research Activities	Time frame (May 15th 2013 to August 10th 2013)						Responsible person
	1st wk	2nd wk	3rd wk	4th wk	5th - 7th wk	8th wk	
Research proposal Writing and submission for approval	▓	▓					Isabirye Isa
Pretesting the tools		▓					Isabirye Isa
Sample out the target respondents (HIV patient and monitoring drugs adherence			▓				Isabirye Isa
Collecting primary data and secondary data				▓			Isabirye Isa Research assit
Assessing Adherence				▓			
Data entry and Analysis					▓		Isabirye Isa
Report Compilation					▓		Isabirye Isa
Report Review						▓	Isabirye Isa
Monitoring evaluation	▓	▓	▓	▓	▓	▓	
Report Submission and approval						▓	Isabirye Isa

Research Budget

The following is the proposed budget for this study of period between one to two months

Research Activities	Quantity	Unit Cost	Amount
Purchase of stationary (note books, pencils, pens,markers)	8	3000= @ Note Bk 500=@ pen	20,000
Professional fees for data analysis		300,000	300,000
Transport costs to and from the hospital	Once a week for 2 months	60,000 per week to and from	280,000
Allowance benefits for Research Assistants	4	50,000/= per DM for 5 days	1,000,000
Typing and printing costs	1 proposal & I report, 4 questionnaires	1000/= each page	200,000
Refreshments in discussions	4 occasions	50,000	200,000
Grand total	**-**	**-**	**2,000,000**

SEMI-STRUCTURED QUESTIONNAIRE FOR HIV/AIDS PATIENTS ON ARVS FACTORS AFFECTING ADHERENCE TO A.R.Vs (ANTI-RETROVIRAL) AMONG PATIENTS ATTENDING KAWOLO HOSPITAL HIV/ART-CLINIC

My name is …………………………………………………………………I am from Kampala international University school of health sciences currently conducting a study on factors responsible for Adherence to ARVs . Please be honest and tell the truth as the information you are going to give is very important and confidential. This study is meant to improve access, identify determining factors for adherence to Anti-retroviral treatment among HIV/AIDS patients.

Demographic data

Gender	Age	Level of education	Marital Status	Employment Status
1 ➔ M 2 ➔ F	1. 18-20 2. 25-35 3. 40-45 4. 50 and above	1 ➔No formal Education 2 ➔Primary 3 ➔Secondary 4 ➔ University 5➔Tertiary	1 ➔Single 2 ➔Married 3 ➔Widow 4 ➔ Divorced	1. Unemployed 2. Self Employed 3. Civil Savant

Place of Residence ………………………………… District ……………………….

PATIENTS' BEHAVIOR and PRESCRPTIONS

Have you heard   about ARVs? 1. Yes   2. No

Please explain

……

………………………………………………………………………………………………………

Do you take ARVs regularly as per prescriptions? 1. Yes   2. No

If no, why?..

Where do you access ARVs?

  1.   Pharmacy   2. Kawolo HIV Clinic   3. TASO Kawolo Hospital
  4. Private Clinic in town   5. Community healthy facility 6. Other (Specify)

What is the distance you take to the above mentioned health facility?

  1. 100 meters   2. 50km   2. 200km   3. l don't know

For how long have you been taking the ARVs?

  1. Less than 1 month   2. 3 month   3. 12 Months   4. 24 Months

In your opinion, what do   you think are the characteristics of the ARVs that you take? (Tick only one and maximum of two answers)

  1. Color of ARVs   2. Test of Drugs   3. Size of drugs   4. Quantity/dosage

Do you think the above mentioned characteristic affect you while on ARVs?

  1. Yes   2. No

If yes, how?

  1. Vomiting   2. Nausea   3. Neuropathy   4.Sweating

A. PATIENTS' LEVEL OF ADHERENCE AND ATITTUDES

How do you rate peoples' adherence and yourself on ARV drugs?

    1. Its relative   2. Adequate 3. Poor

    State a reason for your answer above

    ……………………………………………………………………………………………

    ………………………………………………………………………………………….

How do people the community view positive patients?

1. Negative attitudes   2. Positive attitudes   3. Others ……………….

State a reason for your answer

……………………………………………………………………………………………………

……………………………………………………………………………………………………

 Can HIV/AIDS be completely cured? 1. Yes   2.No

 Can HIV/AIDS be partly treated?   1. Yes   2. No

b) If yes, how?..

When did you last take Ant-retroviral drugs?

Data …………………………   Month ………………………………Year…………………..

refer to *(10 cm long visual analogue scale)*

Did you take ARVs in the last two days? 1. Yes   2. No

If no, why do you think you missed particular days in taking the drugs?

    1. Lacked care/support   2. Misunderstood the Instructions

    3. Lack of food   4. Work/ home duties 5. Stigma   6. Feeling better

    7. Logistics and costs   8. Distance to Kawolo clinic

B. OTHER FACTORS   AFFECTING ADHERENCE TO ARVS

Knowledge about HIV and ARVs

1. Have you heard about HIV? 1. Yes   2. No

2. Have you heard about ARVS (If no in 1 & 2 skip to 5)

1. Yes   2. No

3. What is the difference between HIV and ARVs?

……………………………………………………………………………………………………
……………………………………………………………………………………………………

4. Do you know any myth or misconception on   ARVs 1. Yes 2. No

b)If yes, list at least 3

……………………………………………………………………………………………………
……………………………………………………………………………………………………
…………………………………

Mention some   other   factors that you think   affect you as an HIV positive patient on ARVs

1. Poor effectiveness of ARVs   2. Nutrition   3.Mental health

 4. Limited income to buy other supportive drugs when sick

5. Limited awareness on ARVs   6. Substance abuse (behavior)

7. Availability of medicine   8. Attitude towards ARVs

What   challenges   have   you faced as an AIDS   patient while getting Anti-Retroviral treatment from Kawolo Hospital HIV/ AIDS Clinic?

……………………………………………………………………………………………………
……………………………………………………………………………………………………

Suggest ways in which access to ARVs and adherence can   be improved in your area

……………………………………………………………………………………………………
……………………………………………………………………………………………………

Thanks for the Information

End

KEY INFORMANT INTERVIEW FOR HEALTH PROVIDERS
RESEARCH TITLE: FACTORS AFFECTING ADHERENCE TO A.R.Vs (ANTI-RETROVIRAL) AT KAWOLO HOSPITAL ART CLINIC:

My name is Isabirye Isa .I am from Kampala International University school of health sciences western campus   currently conducting a study on factors responsible for Adherence to ARVs. Please be honest and tell the truth as the information you are going to give is very important and confidential. This study is meant to improve access, identify determining factors for adherence to Anti-retroviral treatment among HIV/AIDS patients.

Date………………………………………..

Started…………………………….   Time ended …………………………………..

Name of the Respondent………………………….Title………………………Age………

For how long have you worked with the Hospital HIV Clinic …………………………….

Number of AIDS Patient in this Clinic: Male…………….. Female ………………….

Questions

1. In your   opinion, do you think the AIDS Patient understand the following?

-   Basic Information about HIV

-   Knowledge about ARVS

-   Difference between HIV and ARVs

2. What is your comment on   the following and their relation to adherence?

•   Availability of medicine s including ARVs in Kawolo hospital

•   Beliefs and Attitudes of HIV patients on ARVS

•   Life styles of HIV patients on ARVS

3. What   is   the level   of   adherence among HIV/AIDS patients on ARVS in Kawolo Hospital HIV/AIDS clinic?

    b) What factors do you think have influenced the above mentioned level of adherence?

4. How   do you think HIV positive patients view   ARVS in terms of the following drug related factors?

       a) Color of ARVs
        b) Test of the drugs
        c) Size of the drugs

5. From the above characteristics, how has   it affected adherence of the clients on ARVs?

6. What relationship is there between characteristics of drugs (ARVs) and HIV patients' adherence?

7. How often do HIV positive patients   take their drugs? (prob)

8. Comment on monitoring of the patients adherence on ARVs

   a) Two- day self-report recall

   b) One-month self-report recall (10 cm long visual analogue scale)

9. What challenges do you think the patients face while on ARVs

10. What strategies have been put in place to address the above challenges regarding adherence of HIV/AIDS patient?

End of Interview

Thanks for the Information

SAMPLE SIZE TABLE

TABLE FOR DETERMINING SAMPLE SIZE FROM A GIVEN POPULATION

N	S	N	S	N	S	N	S	N	S
10	10	100	80	280	162	800	260	2800	338
15	14	110	86	290	165	850	265	3000	341
20	19	120	92	300	169	900	269	3500	246
25	24	130	97	320	175	950	274	4000	351
30	28	140	103	340	181	1000	278	4500	351
35	32	150	108	360	186	1100	285	5000	357
40	36	160	113	380	181	1200	291	6000	361
45	40	180	118	400	196	1300	297	7000	364
50	44	190	123	420	201	1400	302	8000	367
55	48	200	127	440	205	1500	306	9000	368
60	52	210	132	460	210	1600	310	10000	373
65	56	220	136	480	214	1700	313	15000	375
70	59	230	140	500	217	1800	317	20000	377
75	63	240	144	550	225	1900	320	30000	379
80	66	250	148	600	234	2000	322	40000	380
85	70	260	152	650	242	2200	327	50000	381
90	73	270	155	700	248	2400	331	75000	382
95	76	270	159	750	256	2600	335	100000	384

Krejcie and Morgan, 1970: p4

Letter of introduction