

**FACTORS INFLUENCING MANAGEMENT OF  
ANTIRETROVIRAL IN SCHOOL GOING CHILDREN – A CASE  
OF NYANG’OMA HEALTH FACILITY, BONDO DISTRICT,  
SIAYA COUNTY**

**BY**

**DAUGHTY EDITH NIGHT**

**A PROJECT REPORT SUBMITTED IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF A DEGREE OF MASTER OF ARTS IN  
PROJECT PLANNING AND MANAGEMENT AT THE UNIVERSITY OF NAIROBI**

**2013**

## **DECLARATION**

This project report is my original work and has not been presented for an award in any other University.

**Signature .....**

**Date .....**

**Daughty Edith Night**

**Reg. No. L50/68669/2011**

This research proposal has been submitted for examination with my approval as the University supervisor.

**Signature .....**

**Date .....**

**Ms. Esther Magambo**

School of Continuing and Distance Education

University of Nairobi

## **DEDICATION**

I dedicate this work to my daughters Natalia Dickson and Emmanuella Poni. Your inspiration, love and support has made all this possible. Thank you all.

## ABSTRACT

The purpose of this study was to assess those factors influencing the management of Antiretroviral Therapy in school going children in Bondo District, Siaya County, Nyang'oma Health Care Facility. The objective of this research is to assess how time factor influences the management of antiretroviral management in school going children, assess related challenges faced by the caregivers of children undergoing antiretroviral therapy, their dietary requirements and how the age of the child influence antiretroviral therapy and management during their schooling. The study employed a cross sectional descriptive survey research and used questionnaires and structured interview guide to collect data. The target population of this research was school going children on antiretroviral therapy and their caregivers who may be HIV positive or not and are accessing antiretroviral treatment and care from Nyang'oma health care facility. The sample size for study was 72 units, 36 adult caregivers and 36 children between the ages of 8 to 18. Data analysis on socio-demographic assessment, antiretroviral management in school going children, choice and place of livelihood by the caregivers of such children, diet requirement for children undergoing antiretroviral therapy, qualitative data, some of the perceived problems and their solutions was done by use of inferential statistics of partial correlation of the independent variables of time, caregivers, diet and age of the child against the dependent variable of effective management of antiretroviral therapy. Major findings of the study depicted that 66.7% of caregivers worked in the same town as the school of the child and had to be home to give medication to ensure proper adherence, 94.6% of the children respondents attended day schools nearby their homes, 86.2% of the children took their antiretroviral at home, 79.3% of the children attended clinic other than their earlier appointment days, 58.6% of the children did not attend co-curricular activities away from school and home, while 71.4% of the children respondents were in primary school and 7.1% were in secondary school. The study concluded that there was a strong relationship between the independent variables, of time, caregivers, diet, age of the child on antiretroviral and the dependent variable, successful management of antiretroviral therapy. It also concluded that time adherence, caregivers to the children under antiretroviral, good diet, age of the child and routine clinic visits are important to the successful management of antiretroviral therapy and that younger children in primary level need more and closer care from their caregivers, teachers and social workers than those children in secondary school in order to solve the challenges of good antiretroviral treatment. The study recommends that more sensitization and capacity building should be done to caregivers of children undergoing antiretroviral since most of them have education level below secondary level and the school teachers since they spend most time with the children. It further recommends that caregivers and teachers should be capacitated in guiding and counseling skills on HIV care, the ministry of health and education should ensure that there is a staff in charge of children undergoing antiretroviral therapy in schools with the school health care facilities upgraded to meet the demands of antiretroviral treatment.

## **ACKNOWLEDGEMENT**

I take this opportunity to acknowledge a few people who made a significant contribution in ensuring successful completion of this proposal. Immeasurable gratitude goes to my supervisor Ms. Esther Magambo for her unrest, exquisite guidance, wisdom and advice coupled with patience. I also want to thank the University of Nairobi for making it possible to successfully come up to this stage. The lectures of the University of Nairobi have also been very instrumental in their support towards preparations and guidance of the entire course and this study. My great thanks also go to Sr. Margaret and Martin of Nyang'oma Health Facility for their tireless efforts. The social workers and the counselors were also very helpful in giving information and valuable materials for this project.

Lastly, I would want to pass my gratitude to my husband Dickson who sponsored my Master's Degree Program and my sister Rehema their overwhelming support. Special thanks also go to colleagues and friends for the love and support accorded to me in order to accomplish this study successfully.

## TABLE OF CONTENT

<b>DECLARATION</b> .....	<b>ii</b>
<b>DEDICATION</b> .....	<b>iii</b>
<b>ABSTRACT</b> .....	<b>iv</b>
<b>ACKNOWLEDGEMENT</b> .....	<b>v</b>
<b>TABLE OF CONTENT</b> .....	<b>vi</b>
<b>LIST OF ABBREVIATION AND ACRONYMS</b> .....	<b>ix</b>
<b>LIST OF TABLES</b> .....	<b>x</b>
<b>CHAPTER ONE: INTRODUCTION</b> .....	<b>1</b>
1.1 Background of The Study.....	1
1.2 Statement of the Problem.....	3
1.3 Purpose of the Study.....	4
1.4 Objectives of the Study.....	4
1.5 Research Questions of the Study.....	4
1.6 Justification of the Study .....	4
1.8 Limitation of the Study.....	5
1.10 Basic Assumptions of the study .....	6
1.11 Definitions of Significant Terms used in the Study .....	6
1.12 Organization of the Study .....	9
<b>CHAPTER TWO: LITERATURE REVIEW</b> .....	<b>10</b>
2.1 Introduction.....	10
2.2 Adherence and ARVT Timing in HIV persons.....	11
2.3 Caring for HIV Positive Children Undergoing ARVT.....	17
2.4 Diet and Nutrition of HIV Treatment in Children.....	20
2.5 Age of Child and Consistency in Antiretroviral Treatment.....	23
2.6 Schooling and Co-curricular Activities for HIV Positive Children .....	26
2.7 Conceptual Framework.....	29
2.3 Summary of Chapter Two.....	30
<b>CHAPTER THREE: RESEARCH METHODOLOGY</b> .....	<b>31</b>
3.1 Introduction.....	31
3.2 Research Design.....	31

3.3 Target Population .....	31
3.4 Sampling Procedure and Sample Size .....	32
3.5 Research Instruments.....	33
3.6 Validity of the Research Instrument.....	33
3.7 Reliability of the Research Instruments.....	35
3.8 Data Collection Procedures.....	35
3.9 Data Analysis Techniques .....	36
3.10 Operationalization Table of Variables.....	37
3.11 Ethical Considerations .....	38
<b>DATA ANALYSIS: DATA ANALYSIS, PRESENTATION AND INTERPRETATION ...</b>	<b>39</b>
4.1 Introduction.....	39
4.2 Response Rate .....	39
4.3 Socio-demographic Information .....	40
4.4: Assessment of the Success of Anti-Retroviral Therapy .....	44
4.5 Time Management of ARVT in School Going Children.....	45
4.6 Assessment of Choice of Livelihood by Care Givers .....	51
4.7 Assessment of Diet Requirements for Children Under ARVT.....	55
<b>CHAPTER FIVE: SUMMARY OF FINDINGS, DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS .....</b>	<b>58</b>
5.1 Introduction.....	58
5.2.1 Summary of findings on Time Management in ARVT .....	58
5.2.2 Summary of Findings on Related Challenges face by Caregivers .....	58
5.2.3 Summary of Findings on Diet requirement of Children on ARVT.....	59
5.2.4 Summary of Findings on Age of the Child and ARVT Management .....	59
5.3 Discussion of the Findings.....	60
5.4 Conclusions.....	61
5.5 Recommendations .....	62
5.6 Areas for Further Studies .....	63
<b>REFERENCES.....</b>	<b>64</b>

<b>APPENDICES .....</b>	<b>71</b>
Appendix I: Letter of Transmittal .....	71
Appendix II: Children Consent Letter.....	72
Appendix III: Caregivers/Parents Consent Letter.....	73
Appendix IV: Consent Form.....	74
Appendix V: Questionnaire for Caregivers .....	75
Appendix VI: Questionnaire for Children .....	83
Appendix VII: Interview Guide .....	91



## **LIST OF ABBREVIATION AND ACRONYMS**

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral
ARVT	Anti-retroviral Therapy
AJAR	African Journal of Aids Research
AMREF	African Medical and Research Foundation
CDC	Centre for Disease Control and Prevention
DHHS	Department of Health and Human Services
HIV	Human Immune Deficiency Virus
KDHS	Kenya Demographic Health Survey
NACC	National Aids Control Council
NATG	National Anti-retroviral Treatment Guideline
PLWHA	People Living With HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
PID	Pediatric Infection Disease
SPSS	Statistical Package for Social Sciences
UNICEF	United Nations Children's Fund
UNGASS	United Nations General Assembly Special Session
UNAID	United Nations Agency for International Development
WHO	World Health Organization

## LIST OF TABLES

Table 4. 1: Response Rate .....	39
Table 4. 2: Gender of Care Givers .....	40
Table 4. 3: Gender of Children .....	40
Table 4. 4: Age Bracket of Care Givers .....	41
Table 4. 5: Age Bracket of Children .....	41
Table 4. 6: Educational Level of Care Givers .....	42
Table 4. 7: Education Level of Children .....	42
Table 4. 8: Residence of Care Giver .....	43
Table 4. 9: Residence of Children under ARVT .....	43
Table 4. 10: Assessment of ARVT by Care Givers .....	44
Table 4. 11: Assessment of ARVT by Children .....	45
Table 4. 12: Administration of ARVs .....	46
Table 4. 13: Public Administration of ARVs .....	46
Table 4. 14: Failing to take ARVs at the Right Time .....	46
Table 4. 15: Type of Schooling .....	47
Table 4. 16: Participation in Co-curricular Activities.....	47
Table 4. 17: Participation in Co-curriculum Activities Away from Home/School .....	48
Table 4. 18: Clinic Visits other than the appointment Date .....	48
Table 4. 19: Assessment of ARVT Management in School Going Children (Care Givers).....	49
Table 4. 20: Assessment of ARVT Management in School Going Children (Children).....	50
Table 4. 21: Care Giver working in the same Town/Centre as the school of the child .....	51
Table 4. 22: Care giver being at Home to ensure medication is given to the children .....	51
Table 4. 23: Medication given by another person other than Care Giver .....	52
Table 4. 24: Children under ARVT would undertake co-curriculum Activities that require them to be absent from home or school.....	52
Table 4. 25: Caregivers would take up jobs that require them to be away from home on daily basis.....	53
Table 4. 26: Assessment on Choice of Livelihood by Caregivers.....	53
Table 4. 27: Assessment on Choice of Livelihood of Caregivers by Children .....	54
Table 4. 28: Source of Livelihood for House Hold .....	55
Table 4. 29: Special Diet as a Requirement for ARVT Management.....	55

Table 4. 30: Assessment on Choice of Diet Requirements (Care Givers) .....56  
Table 4. 31: Assessment of Choice of Diet Requirements (Children).....57

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 Background of The Study**

The Government of Kenya declared HIV and AIDS a national disaster in 1999 and as result the National AIDS Control Council (NACC) was formed with the support of the President of Kenya to fight the disease and its impacts on the Kenyan community. The declaration enlightened Kenyans to realize that the fight against HIV and AIDS is a universal effort and should become every individual's effort, and most importantly as parents, since the nation is built and founded on the family unit.

The United Nations General Assembly Special Session (UNGASS) on June 27, 2001, called on all United Nations agencies and Non-Governmental Organizations to incorporate as a matter of urgency HIV and AIDS prevention, care and awareness into their strategic plans after declaring it a global disaster. The move highlighted the need for all nations to stop the HIV prevalence rate from rising and the prevention of HIV and AIDS transmission to new born babies and the subsequent health care services to infected adults and children (UNGASS, 2008). The management of HIV and AIDS essentially entails the use of Anti-Retroviral drugs for the treatment of opportunistic infections and boosting the immune system of the body.

It was estimated in 2006 that 2.3 million children under the age of 15 years were living with the HIV, mainly as a result of mother-to-child transmission of HIV (MTCT) and that more than 90% of these children were living in sub-Saharan Africa (UNAIDS, 2006). An estimated 3.4 million children were living with HIV at the end of 2011, 91% of them in sub-Saharan Africa (WHO, 2012). Most of these children acquire HIV from their HIV-infected mothers during pregnancy, birth or breastfeeding. The number of children receiving Antiretroviral Therapy increased from about 456 000 in 2010 to 562 000 in 2011, but this represents coverage rate of only 28% among children in need of pediatric ARVT. According to the Kenyan government, an estimated 184,000 children were living with HIV by the end of 2009; 24 percent of those requiring antiretroviral treatment had access to them. Kenya is making gains in terms of the number of children on HIV treatment - 20,500 were on ARVs in 2008, growing to 28,000 by 2009 (NACC, 2008)

The United Nations Agency for International Development (UNAID) Global report 2012 established that access to HIV and AIDS treatment was on the rise but the proportion of eligible children receiving Anti-Retroviral therapy was much lower. This meant that more children continued to die as a result of HIV and AIDS. According to UNGASS 2010 “Country Progress Report – Kenya”, in 2008/09 HIV and AIDS prevalence among women was twice as that of men. Women as mothers are responsible for nurturing pregnancy and this therefore meant that newborns and infants equally stood a higher chance of acquiring HIV and AIDS from their mothers.

Children are usually tested at birth, after six weeks and at nine months according to NACC. Some mothers are also not tested during pregnancy due to fear that if found HIV positive it meant that their unborn child would also be HIV positive. Others have to travel very long distances to access the HIV and AIDS testing services (AIDS Newsletter, 1989). This therefore meant that such children once borne stood higher chances of being infected by their mothers with HIV and that some died before their first birthday. Others lived on and later on their mothers came to terms with accessing the Anti-Retroviral Therapy for the sake of their children’s’ lives, seeing more children under the Anti-Retroviral therapy within the school going age, primary and secondary.

There is a great consensus among leading organizations that Anti-Retroviral therapy should be initiated early in all infants and children infected by HIV (African Press International, 2009) Therefore, this explains the rising numbers of children accessing the Anti-Retroviral therapy into their school going age. It is challenging to maintain adherence on the part of the children since the children rely on their caregivers to administer to them the medication. Some change treatment, as they grow into adolescence, and they can hardly cope with the many drugs they are expected to take," said Dr Andrew Suleh, medical superintendent at the Mbagathi District Hospital in the capital, Nairobi, 2008. Experts say a combination of factors create treatment failure and put children's lives at risk, including poor adherence, long-term use of Anti-Retroviral, and improper actions by health workers, who may miss or ignore the first signs of treatment failure in children rather than referring them for a change of treatment.

This research endeavors to assess the challenges of Anti-Retroviral therapy in school going children and their caregivers which if minimized would increase ARVT adherence and hence its effectiveness.

## **1.2 Statement of the Problem**

Strict adherence to ARVT instructions is very critical to achieve effective treatment and realize the benefits of the medication. However, there are factors that affect the effective management of ARVT in school going children. ARVT brings with it some challenges to both the children undergoing the therapy and their caregivers. This is because the medication has to be taken at specific times in the morning and evening, for example 7.00 am and 7.00 pm without failure. The caregiver or parent and the child must be at home or convenient place for the administration of the medication. The caregiver must also be economically stable to be able to effectively assist the child with the therapy. The children on ARVT have to attend schools normally just like other children despite their status and be available at specific times to take the medication. It therefore means that many or perhaps all of them may not attend boarding schools, get involved in extra curricula activities that require the child to spend out from home or be away at the time of taking the medication. Their school attendance is sometimes interfered with due to clinic visitations and follow ups. The parents or caregivers have limited choices for employments since they may only accept employment that will allow them to be available in time and every day to give the medication to the children and make routine clinic visits. These children have specific dietary requirements that call for the caregiver to be economically stable since the therapy is a life-long commitment. It may be difficult to transfer the administration of the ARVs to a second party by the caregiver due to confidentiality. Cost implications brought about by the ARVT management like money for transport for visits to clinic and adherence and good nutrition are among other factors. This study assessed the factors that influence the effective management of ARVT especially in school going children.

### **1.3 Purpose of the Study**

The purpose of the study is to assess factors influencing the management of antiretroviral therapy in school going children.

### **1.4 Objectives of the Study**

1. To assess how time factor in ARVT management affects adherence in school going children
2. To establish the related challenges faced by caregivers of schooling children on ARVT in the choice of their livelihoods.
3. To identify the dietary requirements of children under antiretroviral therapy.
4. To investigate how age of school going children affects ARVT management

### **1.5 Research Questions of the Study**

1. Does time factor affect anti-retroviral therapy adherence in school going children?
2. Do caregivers of school going children undergoing anti-retroviral therapy encounter any challenges in choice of livelihoods?
3. Do children under antiretroviral therapy require special diet for effective ARVT management?
4. Does the age of a school going child undergoing ARVT affect its management?

### **1.6 Justification of the Study**

It is without doubt that HIV and AIDS has been an area of major concern globally that has seen the fight to have sufficient access to ARVT. Unemployment has also remained one of the most challenges in the development process in Kenya today. It has been reported that Kenya's unemployment rate is approximately 40 percent. (Labour force survey, 2011). Caregivers of children undergoing Anti-Retroviral are not exempted from this situation. Co-curricular activities are an essential part of a child's development and education and they present many opportunities to students for discovering and developing talents that approximate life in the adult community (Larson, 2006). They permit students to apply knowledge acquired in formal courses

and to acquire concepts of democratic life. (Barbieri, 2009). Some of the co-curricular activities require the students to travel away from their schools and homes and spend more than one night out. Adherence to Anti-Retroviral treatment is essential to maintain long-term health benefit and avoid development of drug resistance (NATG 2004). Thus, monitoring and support of adherence is essential and caregivers or parents have an important role in this.

The result of this project study will be used by the Government of Kenya in improving policies for children living with HIV, Ministry of Labour in enacting employment terms for caregivers of such children, Medical scientist in researching further into kinds of therapy that may call for less restrictive adherence and other social and academic institutions to enable the children live normal lives and attend their school normally.

### **1.8 Limitation of the Study**

The researcher limited this study to cover South Sakwa location, (Nyang'oma division, Bondo District in Siaya County). The data collected will come from caregivers of children on Anti-Retroviral therapy that are between 4 – 18 years of age and are already aware of their HIV status. The care givers were the parents or any person ensuring the child adheres to all of the requirements of ARVT management. The study endeavored to find out any factors that influence the management of ARVT in school going children. There are support group discussions every Mondays, Tuesdays and Thursdays of the month in the HIV and AIDS care clinic and a good number of children undergoing the AVR therapy and their caregivers come to share their experiences. This study used the support groups as sample for the research.

This research endeavored to employ best practice and good ethics in conducting the study, however there were some limitations that were faced during the research. The respondents of the study came from mixed group of children and adults who are their caregivers; The researcher in collected data from the support groups meetings held at the HIV and AIDS care clinic, the support groups only meet for the three days in a week hence limited time for the study: Financial burden of meeting the logistical costs to conduct the study, printing and buying of materials that was used during the study. However, the researcher took authorization from the head of the pediatric department at the care clinic. Before commencing with any discussions with the minor respondents, the researcher assessed the willingness of the children to give right information.



During collection of data, the researcher encouraged use of only one name preferable a fictitious name by respondents and ascertain to the respondents that all data collected from them is confidential and will only be used for analysis and generalization of findings. The researcher tried to attend most of the support group discussions held at the care clinic in order to gain trust of respondents and to get ample sample size. The researcher outlined a work plan and exercise adherence to time in order to meet the deadlines of the research submission. Due to financial constraints, the researcher budgeted for materials to be used during the research and logistical requirements and sourced funding from family and friends.

### **1.10 Basic Assumptions of the study**

The study of Nyang'oma division will represent a sample population of children undergoing anti-retroviral therapy in Kenya. The respondents will give information willingly and truthfully. This study also assumes that children undergoing anti-retroviral therapy depend on their caregivers for ARV adherence, clinical visits, nutritional feeding and general care for ARVT effective and efficient management.

### **1.11 Definitions of Significant Terms used in the Study**

<b>Factors Influencing:</b>	They are the things (situations, conditions, state etc), that contributes or has an influence on the outcome of something. In this study, they are the conditions that contribute to the outcome of ARVT management in school going children.
<b>School Going Children:</b>	Is any child who attends an educational institution for the purpose of learning through formal education. The institution may be day or boarding. In this study the children will be between 4 – 18 years of age.
<b>Management of ARVT:</b>	It is ensuring that the recipient of the treatment adheres to the time schedule for taking medication, correct dosage, behavioural changes, nutritional requirements, clinic visits and follow-ups.
<b>Time:</b>	A limit period during which an outcome, process or condition exists or takes place. It is the exact times that the ARVs must be given to the child, in the morning and in the evening for example 7.00a.m and 7.00p.m

**Adherence:** Is taking all the ARVs in the correctly prescribed doses at the right time and in the right way observing any dietary restriction.

**Caregiver:** Any person that takes the responsibility of a child to ascertain that

the child participates in her/his daily activities including schooling

**Age of child:** Zero to eighteen number of years from birth. This study will discuss children between the ages of zero to eighteen but targets ages between four and eighteen for sampling.

**Diet in HIV and AIDS:** The various nutritional requirements needed by people living with HIV and AIDS (PLWHA) and are on ARVT to improve their health.

**AIDS:** A progressive immune deficiency caused by infection of CD4+ T cells with the human immune deficiency virus (HIV).

**CD4+:** Are first-line defense against bacteria and viruses. They automatically become active once any kind of infection is detected and launch an immune response to attack any invader or foreign object.

**Optimal Adherence:** Taking the prescribed medication  $\geq 95\%$  of the time. In this study it will mean Limitation of the study that the child adheres to the ARVs above 95% in every month.

**Health Facility:** It is a place that provides health care services. In this study, Nyang'oma health facility will mean the clinic where HIV infected children and adults, access psychological, social and clinical HIV treatment and care. It is in South Sakwa location, Bondo District, Siaya County within Nyang'oma Mission Complex.

**Prevalence:** The number of affected persons present in the population at a specific time divided by the number of person in the population at that time.

<b>Mortality Rate:</b>	Mortality is a measure of the number of deaths (in general, or due to a specific cause) in a population, scaled to the size of that population, per unit of time.
<b>Morbidity:</b>	This is the percentage of people in a population that get sick of a particular disease
<b>ARV Therapy:</b>	Is the treatment of people infected with human immunodeficiency virus (HIV) using anti HIV drugs. The drugs are used in order to reduce the likelihood of the virus to developing resistance.
<b>Pre Exposure Prophylaxis:</b>	Is any medical or public health procedure used before exposure to the Disease causing agent, its purpose is to prevent, rather than S cure a disease.
<b>Immune System:</b>	It is a network of cells, tissues, and organs that work together to defend the body against attacks by “foreign” invaders.
<b>Hemophilia:</b>	Is a bleeding disorder whereby the blood does not clot normally.
<b>Viral Suppression:</b>	Halting of the function or replication of a virus.
<b>Asymptomatic:</b>	Asymptomatic means that a patient is a carrier of a disease or infection but experiences no symptoms.
<b>Mal-absorption:</b>	Mal-absorption is usually the inability to absorb certain sugars, fats, proteins, or vitamins from food. It can also involve general mal- absorption of food.
<b>P-Value</b>	This is the level of significance within a statistical hypothesis test and is a representation of the probability of the occurrence of a given event. The smaller the P-Value, the stronger the evidence.

## **1.12 Organization of the Study**

The study is structured in five chapters. Chapter one deals with introduction of the study giving the pillars upon which the study is based. It had the following subsections: background of the study, statement of the problem, objectives of the study, research questions, justification of the study, scope of the study, limitation of the study and definition of significant terms.

Chapter two is literature review and is based on the following subsections: introduction, theoretical background on the factors influencing the management of antiretroviral therapy in school going children and finally conceptual framework and summary of the chapter.

Chapter three is research methodology and has the following subsections: an introduction, research design, target population, sampling size and sampling procedure, research instruments, validity and reliability of research instrument, data collection procedures and finally data analysis techniques and operationalization of variables.

Chapter four is data analysis, presentation and interpretation and has the following subsections: introduction, response rate, socio-demographic information, assessment of ARVT management in schooling children, assessment of choice of livelihood of caregivers and diet requirements for children, qualitative data analysis and perceived problems and solutions.

Chapter five is the summary of findings of the study variables: place of work for caregivers, caregivers, and their presence at home for administration of medicine, inadequate source of livelihood for caregivers, school attended by the children respondents, clinic visits and taking part in co-curricular activities by children under ARVT. This chapter also has the conclusion of the study on: the relationship of the study variables, importance of caregivers, importance of balanced diet, more and close care for younger children and importance of routine clinic visits. Lastly it has the recommendations for further study on; male caregivers, single parent caregivers and ARVT management in secondary school.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

The first cases of AIDS (Acquired Immune Deficiency Syndrome) were identified among gay men in the United States, acquiring the designation, GRID (Gay-Related Immune Deficiency) in 1981. However, scientists later found evidence that the disease existed in the world for some years prior. In 1982 cases of AIDS began to be reported by fourteen nations. And, as early as 1982, CDC (Centre of Disease Control) received its first report of "AIDS in a person with hemophilia (from a blood transfusion), and in infants born to mothers with AIDS (CDC, 1985). CDC began the awareness and publication of morbidity and mortality rates of AIDS on weekly reports globally.

In 1982 AIDS is named and vertical (mother to child) and heterosexual transmission were recognized. The following year a virus is identified that is suspected of causing AIDS. It is later named HIV and World Health Organization (WHO) HIV surveillance starts. In 1984 the first case of HIV in Kenya is identified and in the following year the National AIDS Committee is established. There was plenty of evidence that HIV was a serious problem in Kenya and that in Nairobi prevalence among Commercial Sex Workers there peaked at 81%. In 1987 the WHO formed the Global Programme on AIDS. The following year, Kenya's Ministry of Health issues guidelines stating that patients should be told their HIV status. By 1990, there were an estimated 7.5 million people living with HIV, globally (WHO 1997).

In 1997 UNAIDS, a Joint United Nations Programme on HIV/AIDS was formed. Then Kenyan Parliament approves a 15 year national AIDS policy and forms the National AIDS Council and sex education plans commenced. By 2000 an estimated 27.5 million people were living with AIDS, globally. Kenya develops a five year National AIDS Strategic Plan and plans AIDS education for all schools and colleges. The Millennium Development Goals (MDG) was adopted by the international community and reducing the spread and impact of HIV were included in this initiative.

HIV has become a pandemic since the first cases were identified over 2 decades ago. It is a major cause of morbidity and mortality in many countries particularly in sub-Saharan Africa (UNAIDS, 2010). Half of children infected with HIV at birth die before their second birthday thus the magnitude of this problem remained hidden for a long time (UNICEF, 2010). The main source of infection for children is mother to child transmission. Kenya's current strategic thrusts are prevention of HIV transmission through universal testing of antenatal mothers, ARV interventions and safe breastfeeding practices. There are approximately 1.2m births per annum with eight per cent of mothers being infected. It is estimated that 150,000 need care and treatment countrywide (Volari, 2008)

In Kenya, HIV prevalence, among adults 15-64 years old, is estimated to be 6.3% (Kenya Demographic and Health Survey 2008-09). Studies have shown that women are more likely to be infected (8.0%) than men (4.3%), and young women aged 15-24 are four times more likely to be infected (6.4%) than young men of the same age group (1.5%). Also according to the United Nations Children's Fund (UNICEF, 2012) the estimated HIV/AIDS prevalence rate among those aged between 15 and 49 years is 6.3 percent. The organization further estimates that about 180,000 children between 0-14 years are HIV positive (UNICEF 2012)

## **2.2 Adherence and ARVT Timing in HIV persons**

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). There were estimated 270,000 people living with HIV in Botswana at the end of 2005. This gave Botswana a prevalence rate of 24.1% the second highest in the world. At the end of 2006 around 84,000 people were receiving ARV treatment. 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).

The latest data gathered from countries around the world tell a story of clear success. Sustained investments in access to antiretroviral therapy by donors and national governments have led to

record numbers of lives being saved in the past six years. In 2011 more than half a million fewer people died from AIDS-related illnesses than six years earlier. It's a dramatic turning point. In 14 countries, AIDS-related deaths dropped by more than 50% between 2005 and 2011. Numbers can quantify, but alone cannot express the impact of each averted death on the whole community, including its children (UNAIDS, 2012)

For the first time, a majority of people eligible for HIV treatment in low and middle-income countries—54%, a record eight million people—were receiving antiretroviral therapy. This means more people than ever who are living with HIV are being helped to live longer, healthier and more productive lives. Lessons learned through the past decade have led to improved collaboration between governments, donors, partners, and a combination of innovation, efficiency and increased domestic investments have seen a return on investment unparalleled in the AIDS response (UNAIDS, 2012).

The part of the world most impacted by HIV, sub-Saharan Africa, has cut the number of people dying of AIDS-related causes by 32% between 2005 and 2011. The largest drop in AIDS-related deaths was in some of those countries where HIV has the strongest grip. In South Africa, 100 000 fewer deaths occurred, followed by nearly 90 000 in Zimbabwe, 71 000 in Kenya, 59 000 in Ethiopia and 48 000 in the United Republic of Tanzania (UNAIDS, 2012). A number of the region's countries with smaller populations but high HIV prevalence have also made significant gains in averting deaths related to AIDS.

Kenya has an estimated 70,000 to 100,000 infants exposed to HIV every year. The current efforts reflect approximately 10 per cent rate of transmission so it is expected that there are 7,000 – 10,000 newly infected children annually. In 2008, 2,500 children were put on treatment. Kenya today has over 400 sites where Early Infant Diagnosis can be carried out. Testing of children is now carried out in immunization clinics at age six weeks, in outpatient clinics and in children's wards. The objective is to test all admitted children and to know the HIV exposure status for all infants at age six weeks. All the ones found to be infected with HIV are put on ARVs. By December 2008 there were 23,000 children on treatment out of an estimated 40,000 who needed it. (UNICEF, 2012)

Children are now central to strategies and actions to avert and address the consequences of the epidemic. It is estimated that more than 1,000 babies continue to be born with HIV every day, many of them destined to die before age two if they do not receive medication (JUNP HIV/AIDS, 2010) Adolescents are still becoming infected with HIV because they have neither the knowledge nor the access to services to protect themselves, and those infected at birth are struggling to reconcile their emerging adulthood with their HIV-positive status. The elimination of new HIV infections and AIDS-related deaths in children is possible, but it will require vision, leadership and system-wide improvements in health-care delivery, as well as deep-seated social change and continued implementation of best practices.

In 2010, WHO issued new recommendations by which many more children with HIV – including all those under the age of 2 will be immediately eligible to initiate antiretroviral treatment. At the same time, increased opportunities to identify children living with HIV have resulted from greater availability of routine HIV testing for children, including early infant diagnosis services, with new policy guidance issued in 2010 that clarifies requirements for testing of infants and young children in health facilities (UNICEF, 2010) There is also greater awareness of the growing epidemic of HIV among adolescents, many of them long-term survivors who were infected as newborns.

New guidelines and better methods to identify children have created opportunities to start many more children on life-saving treatment. However, new data reveal that this potential remains largely unrealized. In 2009, there were 2.5 million children under age 15 living with HIV. Although the number of children in low- and middle-income countries receiving ART increased from 275,300 in 2008 to 356,400 in 2009, this is still only 28 per cent of the 1.27 million children currently estimated to be in need under the new guidelines. Progress in decentralizing pediatric treatment to lower-level facilities and in training providers at all HIV treatment sites to treat infants and children as well as adults has been unacceptably slow. In many settings, pediatric ARVT is relegated to specialized facilities located in urban areas or high-volume centres (UNICEF, 2010).



In 2001, 5.7 million young people aged 15–24 were estimated to be living with HIV. At the end of 2009, that number had dropped to 5.0 million. Further, an estimated 890,000 new infections occurred among young people aged 15–24 in 2009 (JUNP HIV/AIDS, 2010).

The American National Institutes of Health, other governments and other organizations recommend offering antiretroviral treatment to all patients with AIDS. Patients initiating antiretroviral therapy should be willing and able to commit to lifelong treatment and should understand the benefits and risks of therapy and the importance of adherence (Thomson, 2012). According to the Department of Health and Human Services (DHHS, 2009) if patients miss doses, drug resistance can develop. Individuals who fail to use antiretroviral properly can develop multi-drug resistant strains which can be passed onto others. Taking HIV treatment requires effort and commitment as drugs must be taken at exact times each day (Peter, 2013). Treatment, care and support can help people to adhere to treatment and address any problems they may have with their treatment (Beardsley, 2009).

Starting HIV treatment is a big step. When to begin treatment depends on one's health, test results, and readiness to take a combination of anti-HIV medications every day at specific times both in the morning and evening (Dybul, 2008). Once you begin taking anti-HIV medications, you will probably need to take them for the rest of your life. Because HIV disease progression in children is more rapid than in adults, and laboratory parameters are less predictive of risk for disease progression, in particular for young infants, treatment recommendations from the DHHS have been more aggressive in children than in adults.

Once treatment of HIV commences and one takes the anti-HIV medications exactly as directed, it's possible to have an undetectable viral load within 3 to 6 months. An undetectable viral load means that the level of HIV in the blood is too low to be detected by a viral load test. You are not cured but still have some HIV in the body. But an undetectable viral load indicates that the anti-HIV medications are working effectively to keep the body healthier and reduce the risk of transmitting HIV (Jain, 2010). According to the Working Group on Antiretroviral Therapy and Medical Management 2009, antiretroviral medications can cause side effects, however, side effects that become unbearable or life threatening call for a change in medications. Interactions

between anti-HIV medications and other medications can increase the risk of side effects (Thomson, 2012).

Close adherence to an HIV treatment allows ARVT to work effectively to reduce the amount of HIV in the body. Skipping medications, even occasionally, gives HIV the chance to multiply rapidly. Preventing the virus from multiplying is the best way to protect one's health. Skipping medications makes it easier for drug resistance to develop. HIV can become resistant to the antiretroviral medications in a person's current treatment or to other, similar anti-HIV medications not yet taken, and limiting options for successful HIV treatment. And drug-resistant strains of HIV can be transmitted to others, too (DHHS, 2009). According to the Working Group on antiretroviral Therapy and medical management 2009, adhering to an HIV treatment regimen can be difficult for several reasons. Some treatment involve taking several pills every day: Other factors that can make treatment adherence difficult include: Difficulty taking medications (such as trouble swallowing pills): Side effects from medications (for example, nausea or diarrhea): A busy schedule, shift work, or travel away from home that makes it easy to forget to take pills; Being sick or depressed. Some people find that adhering to an HIV treatment becomes more difficult over time, and children are not exempted from this. Poor treatment adherence is another reason for HIV treatment failure. Skipping medications allows HIV to multiply, increasing a person's viral load. To reach and maintain an undetectable viral load, it's important to closely follow your treatment. Poor treatment adherence can also give HIV a chance to change form, leading to drug resistance (Beardsley, 2009). Once one starts treatment, they should have a viral load test within 2 to 8 weeks and then once every 4 to 8 weeks until the viral load is undetectable. The viral load test should be done only every 3 to 4 months once your viral load is undetectable. If one has an undetectable viral load for more than 2 or 3 years, your health care provider may recommend viral load testing once every 6 months (DHHS, 2009).

Most people do not adhere to the treatment recommendations of their health-care practitioners all of the time. Adolescence is a particularly vulnerable age for non-adherence in those who have chronic health conditions such as HIV infection. Poor adherence leads to poor health outcomes in many diseases such as asthma and diabetes. However, HIV treatment is unique in its requirement for 90% to 100% adherence to drug regimens to avoid the development of viral

resistance and the loss of future efficacy of anti-HIV drugs. The need for intensive education and support for children and adolescents living with HIV infection cannot be overstated (DHHS, 2009). Planning treatment collaboratively with the patient and family strengthens the therapeutic relationship and promotes successful adherence and HIV control. Enlisting adult support in the home is beneficial regardless of the patient's age. Frequent clinical follow-up with viral load testing allows the clinician to identify problems early and help patients and families find successful solutions.

A 2009 study commissioned by UNESCO on the quality of education and learning outcomes in Eastern and Southern Africa, including HIV and AIDS knowledge, confirmed low knowledge levels among children in the upper-primary school grades despite the existence of good-quality curricula to educate young people about HIV and AIDS (Dolata et al, 2010). There are many reasons for this, including poor pre- and in-service teacher training, lack of use of participatory learning methods, weak or non-existent support from headmasters and other leaders, few incentives to use classroom time to teach a topic that is not subject to examination, and educators' discomfort around the subject matter.

Clinical benefits of early treatment include: control of viral replication easier to achieve; delay or prevention of immune system compromise; lower risk of resistance with complete viral suppression; possible decreased risk of HIV transmission (Republic of Kenya, MoH, 2005). Positive impact of ARV treatment on health was demonstrated even in patients with advanced stages of HIV infection (Hung et al, 2002). Antiretroviral therapy (ARVT) adherence is a strong predictor of biologic (virologic and immunologic) and clinical outcomes in HIV, including quality of life, HIV progression, hospitalization and death (Sharon et al, 2006). The risks of early treatment include: greater cumulative drug related adverse effects; earlier development of drug resistance if viral suppression is sub optimal; limitation of future antiretroviral treatment options (Republic of Kenya, MoH, 2005). Clinical benefits of delayed treatment include: avoidance of treatment related negative effects on quality of life and drug related toxicities; preservation of future treatment options; delay in development drug resistance associated with treatment failure; more time for the development of more potent, less toxic, and better studied combinations of antiretroviral drugs (Republic of Kenya, MoH, 2005). The risks of delayed treatment include:

possible risk of irreversible immune system damage; the increased possibility of progression to AIDS; the increased risk of HIV transmission to others during a longer untreated period (Republic of Kenya, MoH, 2005)

### **2.3 Caring for HIV Positive Children Undergoing ARVT**

Supporting the well-being of PLWHA is important from a practical perspective and crucial from a human rights perspective (Reddington, 2010). Caring for people with HIV and AIDS is an enormous task. The fact that there is no cure for the disease, adds an additional burden to caregivers when they see the numbers of those infected increase every day (Armstrong, 2009). According to Armstrong, caregivers are a precious resource that needs to be protected against stress and burnout. Providing ARVT has many benefits, which include a decrease in the occurrence of all HIV related illnesses in PLWHA, and reducing the burden on the health system and caregivers, all leading to improvement in the quality of life of PLWHA and their families (Naar et al, 2009). Other benefits include allowing PLWHA to continue being productive members of their family and communities for as long as possible, thus relieving those who were caring for them when they were incapacitated, and also preventing the further spread of HIV (Dunn et al, 2009).

HIV infection in children represents a family and often a multigenerational disease. For a child with prenatal HIV infection, mother and child may both be on ART. Other family members may also be infected and on medications. HIV may be only one of many problems the family is dealing with (Mellins et al, 2009). Younger children typically assume less responsibility than older children for medication-taking and may not know their HIV diagnosis (Mellins et al, 2009). For many reasons, including disclosing the biological mother's HIV status, stigma, and emotional impact, and/or discrimination, caregivers may wait until early adolescence to disclose HIV status to the child, which may adversely affect adherence to ARVT (Mellins et al, 2009). As children enter adolescence, they often assume increasing responsibility for medication administration, with the primary caregiver's role reduced (Mellins et al, 2009). Caregiver report of greater youth responsibility has been associated with poorer adherence, suggesting that transition of responsibility is not always successful and reflecting the need to better understand and facilitate this process (Naar et al, 2009). Knowledge about barriers to adherence to

antiretroviral (ARV) medications, as independently reported by children and caregivers, may help clarify factors contributing to difficulty transitioning responsibility and inform potential interventions to improve ARVT adherence (Naar et al, 2009)

As a caregiver of an HIV positive child, there are many different challenges to deal with aside from disclosing. HIV positive children require a lot of care and support in order to stay healthy, like having a well-balanced diet for the ARV drugs to be effective, making sure they are staying clean and hygienic, and maintaining the strict schedule that medications require (Mellins, 2009). Many common challenges among caregivers were the inability to provide enough nutritious food to their child because they have a very low income or no job at all (Bechmann, 2010). Putting food on the table is hard enough, making it well balanced is an entirely different story. However one of the biggest challenges is adherence for the children because they depend on someone else to give them their medication (Naar, 2009). Because ARVs require a rigid schedule and the medications must be taken at the same time every day, caregivers struggle with being busy with other things. Sometimes even the children remind the caregivers to take the medication. As a caregiver of an HIV positive child, there are many different challenges to deal with aside from disclosing (Katherine, 2010). HIV positive children require a lot of care and support in order to stay healthy. Many common challenges among caregivers were the inability to provide enough nutritious food to their child because they have a very low income or no job at all.

Due to the stigma surrounding the disease, the number of people that can support and take care of the child when the caregiver is unavailable is limited if disclosing is a problem. While psychosocial support for children is critical in accepting their status, caregivers also need psychosocial support (Katherine, 2010). If they are the mothers then they too are HIV positive and dealing with both statuses at the same time, trying to take care of their child and themselves. If the caregiver is struggling with their status, it can cause a lot of stress and anxiety in both the caregiver's and child's life (Collins, 2009).

According to the 2009 population and housing census, 34% of the Kenyan populations are aged between 15 and 34. This is a substantial workforce that could contribute significantly to economic growth. However, much of this labour force is unutilized. In Kenya today, unemployment stood at 25% for the age group 15-19, 24.2% for 20–24-year-olds, 15.7% for

those aged 25-29 and 7.5% for the age group 30-34 (KIHBS, 2005/6). It is devastating to note that youth unemployment constitutes 70% of total unemployment in Kenya. With this kind of data it is clear that unemployment is still a major problem in Kenya and that it affects all groups of people, youth and adults who among them are HIV positive and are also caregivers to children living with HIV and AIDS today. Despite this, these children still need to attend school which must be catered for by their caregivers through their various sources of livelihoods.

It is well established that HIV, which has usually been associated with sex, illness and death, has become a prime target for fear and accompanying negative attitudes and behaviors in most societies (Merson et al, 2008). Stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of the construction of stereotypes, the differentness, separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. Thus, the term stigma is applied when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold (Link et al, 2009).

Stigmatization processes exist within power inequalities and stigma also creates them; the effect for those who are stigmatized is a contraction in economic, social, and political life-chances (Link et al, 2009). The dimension of power is critical for understanding stigma: when examining employment specifically, it is the power differences within the workplace — between those living with HIV and those who discriminate against them (whatever the HIV status of the person perpetrating the discrimination), leading to such outcomes as job termination or refusal to hire. There are also high chances that people living with HIV and AIDS in Kenya today still face such stigmatization and discrimination at hiring and termination of work. There are also higher chances that most children born of HIV virus have parents who are HIV positive as their caregivers (Armstrong, 2009).

Employment discrimination based on HIV status is pervasive in every region of the world and it includes forced disclosure of sero status, exclusion in the workplace, and job termination. Employment discrimination based on HIV status, particularly exclusion in the workplace and job termination, was reported in all the African sub regions surveyed. PLWHA in Kenya and Zambia reported significant barriers to employment, including discrimination in hiring, loss of

promotions, and job termination because of HIV status (AJAR, 2011). While some employers have certainly created workplaces that provide support and employment protection for employees living with HIV, it is clear from the survey findings reviewed that far too many individuals in Africa work in environments with the types of discriminatory practices (i.e. forced disclosure for employment, and exclusion in the workplace or job loss following disclosure (Kelly et al, 2009). The workplace serves as an important location of economic activity, on which individuals depend for social and individual development, and often for their very survival (Sprague & Dickinson, 2008).

Prior to 2003, school was a big burden to many Kenyan parents. Actually many children of school-going age were out of school. Kenya today is enjoying free primary education when in January 2003 President Mwai Kibaki re-introduced free primary education which previously existed before the mid-80s when the government adopted cost sharing measures that led to a minor level of school fees charged by primary schools for text books, Parent and Teachers Associations (PTA), and co-curricular activities. Since 2003, education in public schools became free and universal (but not compulsory). Despite this there are still certain cost implications of schooling that parents must pay for and not all children attend public schools.

#### **2. 4 Diet and Nutrition of HIV Treatment in Children**

According to the European Collaboration Study (2008), HIV is frequently linked to growth failure in children and that Children were on average around 7 kg lighter and 7.5 cm (3 inches) shorter than uninfected children at ten years old. One factor behind HIV-related weight loss is increased energy expenditure. Though no one knows quite why, many studies have found that people with HIV tend to burn around 10% more calories while resting, compared to those who are uninfected. People with advanced infection or AIDS (particularly children) may expend far more energy (Betterham, 2009). Faster metabolism is not the only problem. In normal circumstances, a small rise in energy expenditure may be offset by eating slightly more food (Crenn, 2007) or taking less exercise (Sheehan, 2008). Other important reasons why people with HIV may lose weight or suffer childhood growth failure include: decreased energy intake or, to put it simply, eating less food. Once HIV has weakened the immune system, various infections can take hold, some of which can affect appetite and ability to eat. Secondly, weight loss or

growth failure can occur when the body is less able to absorb nutrients – particularly fat – from food, because HIV or another infection has damaged the lining of the gut. Diarrhea is a common symptom of such mal-absorption (Wenke, 2010). There is strong evidence that malnourished people are less likely to benefit from antiretroviral treatment. For those with severe malnutrition the risk was six times greater than for those of healthy body weight (Zachariah, 2009).

In Africa under nutrition is a significant cause of morbidity and mortality in children under 5. Moreover, under nutrition is endemic in sub-Saharan Africa, with approximately 10 percent of children under 5 suffering from moderate and severe wasting, 40 percent with moderate and severe stunting, and 29 percent with moderate and severe underweight (UNICEF, 2012). Malnutrition compromises children's health and makes them more susceptible to illness and death. Approximately 17 percent of children in sub-Saharan Africa die during the first five years of life, largely from infectious diseases including acute respiratory infections, diarrhea, and malaria.

The burden of under nutrition among young children has been compounded by HIV and AIDS. By the end of 2005, an estimated 2.3 million children worldwide were HIV positive, almost 90 percent of them in sub-Saharan Africa (UNAIDS, 2006). The synergy between under nutrition and HIV is well documented. Under nutrition weakens the immune system, increasing vulnerability to HIV infection, and HIV compromises nutritional status and increases vulnerability to infection. Children infected with HIV are more vulnerable to under nutrition and growth failure. Adequate nutrition can help delay the progression of HIV if it starts early in the disease stage when the child is asymptomatic.

HIV-infected children born to HIV-positive women have early and sustained stunting or low height for age, although they are usually not wasted. An HIV-infected child faces a number of problems with nutrition implications. The following problems need to be addressed immediately: Inadequate food intake because of poor appetite, mouth ulcers and oral thrush, high selectivity around food choices, abdominal pain, and decreased interest in food; Increased nutrient losses because of mal - absorption, diarrhea, vomiting; Increased nutrient needs because of the hyper-metabolic and hyper-catabolic effects of infections, and HIV itself: Socioeconomic factors such as poverty, illness of the parent(s), and food Insecurity (UNAIDS, 2006).



Because of the many complications experienced by the HIV-infected child, nutrition care and support should be an integral component of treatment. Early nutrition intervention can help delay HIV disease progression or death in the HIV-positive child. The HIV-infected child is at very high nutritional risk, as noted. HIV infection causes excess nutrient losses and mal - absorption, further increasing nutritional requirements and the risk of under nutrition (WHO, 1997). Frequent infections increase energy needs as a result of the added metabolic stress of fever and often increased respiratory rates (Nutrition and HIV, 2011). The child may also have urinary losses of protein that increase protein requirements. HIV-related infections such as diarrhea have severe nutrition consequences that lead to appetite loss, weight loss, and wasting. Early diagnosis of HIV, prompt diagnosis and management of infections, and use of antiretroviral drugs (ARVs) where available can improve nutrition and health for the child (Oneill et al, 2003).

Without food or the right nutrition, taking antiretroviral drugs can be so painful that people simply don't. In a choice between taking pills with no immediate or obvious effect, and eating food to survive, food will almost certainly take priority every time. A health worker in Zimbabwe, where malnutrition is widespread, explained that taking antiretroviral drugs on an empty stomach is like digesting razor blades. The result is that many simply do not take them (The Guardian 2009). In resource-poor countries, treatment in children is made more difficult because many children with HIV are severely malnourished. Very little is known about how best to treat such children, and in particular whether it is best to start antiretroviral treatment before or after nutritional rehabilitation (Heikens, 2008). The World Health Organization recommends treating the malnutrition first, but stresses that "further research on these matters is urgently needed (WHO, 2010)

However, in general the recommendations for people living with asymptomatic HIV infection are much the same as for everyone else, meaning a healthy, balanced diet (WHO, 2010). But three differences are worth noting: Because people with untreated HIV tend to burn more energy, the total number of calories should be around 10% higher than the usual guideline amounts, and up to 30% higher during recovery from illness: Many experts recommend a daily multivitamin (usually without iron, except in menstruating women or people with iron deficiency).

Nutritional assessment helps HIV positive people receive appropriate treatment, care and nutritional support. Even in the poorest settings, according to the World Health Organization. Screening for nutritional status and assessment of dietary intake should be included routinely in HIV treatment and care for adults and children (WHO, 2008). In the US, the Department of Health and Human Services advises that, ideally, all people living with HIV should have access to the services of a registered dietician with expertise in HIV/AIDS (HRSA, 2009). A dietician can assess the patient's diet, lifestyle and nutritional status, and provide counseling and referrals

The actions listed below can help caregivers increase the caloric intake of HIV-infected children who may be ill frequently and suffer from fever, mouth sores, and decreased appetite: Increase the frequency of meals (6–8 small meals throughout the day): Feed high-energy and nutrient-dense foods (e.g., fortified, germinated, or fermented foods): If available and the child does not have diarrhea or mal - absorption, high-protein foods such as margarine, butter, vegetable oil, dry milk powder, cooked eggs, cheese, or peanut butter to foods for the child: Feed a variety of locally available fruits, vegetables, legumes, animal products, cereals, and fortified foods: Give the child nutritious and energy-dense snacks between meals: Give the child soft foods that require less chewing or are easy to eat (WHO, 2010).

Another challenge is the fact that many settings lack the human resource capacity to provide the care and support needed to ensure survival of the HIV-infected child. Early nutrition intervention can help delay HIV disease progression or death in the HIV positive child (Kelly et al, 2009). Components of nutrition care and support for young HIV-infected children include nutrition screening and assessment, management and treatment of common diet-related HIV symptoms, improved diet to meet needs for growth and development, promotion of good hygiene and food and water safety, treatment of severe malnutrition, and provision of ARVs (Nutrition and HIV, 2011). All the above nutritional factors are with no doubt calling for a closer supervision of the child by the caregiver and economic and financial empowerment.

## **2.5 Age of Child and Consistency in Antiretroviral Treatment**

Anti-retroviral therapy not only in children has been proved to enhance and improve the quality of life of people living with HIV and AIDS. Children and adolescents are an ever-growing part of the human immunodeficiency virus (HIV/AIDS) pandemic. In 2007, an estimated 2.1 million

children younger than 15 years were living with HIV, and 290,000 children died from the disease in 2005 (WHO 2006). HIV/AIDS takes an enormous physical toll on those infected by the virus as well as those who care for them. However, the social impact of the pandemic is just as significant (Oneill et al, 2003). The psychological and social effects of HIV/AIDS are magnified in today's youth. Children involved in the pandemic face a set of psychological and social issues that must be addressed, not overlooked because they too are entitled to a normal life like their counterpart children (Rew, 2007).

In many parts of the world, HIV/AIDS is still viewed solely as a terminal illness, a disease from which there is no recovery. However, with the ever-improving availability of antiretroviral therapy, HIV is increasingly recognized as a chronic, rather than terminal, illness (Kuo, 2009). This transition requires psychological adjustments, especially in the pediatric and adolescent populations in school going (Naar, 2009). Children born and living with HIV virus grow into adulthood if well taken care of.

Unlike acute conditions, which develop and resolve within a limited amount of time, chronic conditions are permanent and usually have no cure (Zachariah, 2009). Because chronic illness persists for an extended time, infected children and their caregivers go through psychosocial stages that can be sources of great stress, including the following: Initial diagnosis; Disclosure of disease status to the child; Difficulties resulting from long-term care, including financial and emotional strain; (Oneill et al, 2003), this in return may impact tremendously into their schooling.

For pediatric patients with HIV, the preceding stages have increased psychological stress. Stigma surrounding HIV negatively affects disclosure; influences daily care of the patient, and may even continue through to the patient's death. With regard to difficulties with long-term care, adherence to HIV medication regimens is extremely taxing on the patient and his or her family (UNICEF, 2009). To prevent resistance, the child must take the medications with a greater than 95% rate of adherence. This task can be difficult for an adult patient and increasingly difficult when the patient is a child or adolescent (UNICEF/UNAIDS, 2004).

The stressors of a chronic illness can be more challenging when the patient is a child. This situation increases the necessity for caregivers and other family members to assist with medical

care and activities of daily living. It therefore means that these caregivers and the children undergoing the therapy must exercise change in their daily lives to suit the adherence requirements (Cherutich, 2008). Children with a chronic illness such as HIV/AIDS face unique challenges that make their lives more difficult. It is important to understand the long-term effects that these challenges can have on the children and their caregivers. With proper support from their health care providers and their community, the challenges of living with childhood HIV/AIDS will be easier to surmount.

Young children need ritual, consistency, and supervision. Making medication taking a ritual the same time, same place and same way each day is comforting for young children. Many families do not realize that they need to supervise children and teens while taking medications. Often children are given responsibility far beyond their years for their HIV and other medications as well as for other family tasks (Volari, 2008). If this is the reality for these children and families, the most realistic and useful care- management intervention may be to provide supports for the older child so that he/she can manage medications safely.

The unique development of adolescents makes caring for them a challenge. The adolescent's approach to illness is often different from that of adults. The concrete thought processes of young adolescents makes it difficult for them to understand and accept the need to take lifelong medications when they are asymptomatic and feel well (WHO, 2009). This is especially true if the regimen includes many pills, needs to be taken several times a day and/or has side effects that make them feel sick. Denial is also common, particularly for adolescents who are recently infected. Having to take medications daily is a reminder that you have this frightening disease, that it is not going away, and you cannot forget that you have it (Dolata, 2010). Children with HIV infection who are becoming adolescents are adolescents nonetheless. Like all teenagers, they struggle for independence from parents and authority figures and want very much to be like their peers and not to stand out or be different. These needs often cause difficulty with treatment adherence. A child who had previously been cooperative and compliant can rebel against parents/caretakers and even against long-term healthcare providers regarding medications or care (UNICEF, 2010). Adherence to medication can be complicated by an adolescent's anger and depression about their HIV diagnosis, an unstructured and chaotic lifestyle which may include

homelessness or limited access to proper nutrition or refrigeration, and a lack of family and social support (Yin, 2008).

Many adolescents who are infected as teenagers face challenges in adhering to medication regimens for reasons that include: denial and fear of their HIV infection, misinformation, distrust of the medical establishment, fear and lack of belief in the effectiveness of medications, low self-esteem (Volari, 2008). Comprehensive systems of care are required to serve both the medical and psychosocial needs of adolescents with HIV infection who are frequently inexperienced with healthcare systems (Oburu, 2009). The care needs to be provided in youth-friendly environments. A realistic assessment of what support systems the youth will need to manage adherence must be incorporated into plans for ART (WHO 2009).

## **2.6 Schooling and Co-curricular Activities for HIV Positive Children**

One cannot say that boarding school is better or Day school in comparison, while both are effective in producing good results in terms of academics, extra-curricular and social interactions some parents find it difficult to give extra-care and time to their children from the drudgery of their routine, and also due to other reasons they send their children to boarding in order to be able to get other livelihood (Dieter, 2004).

There are a number of benefits in a boarding School; Boarding (or residential) schools are in this research defined as schools where students stay internally during the school week (and sometimes during the weekend/ holidays) Boarding schools have dormitory facilities and facilities for eating, studying and recreational activities. Usually there is accommodation for supporting and/ or teaching staff as well (Dieter, 2004).

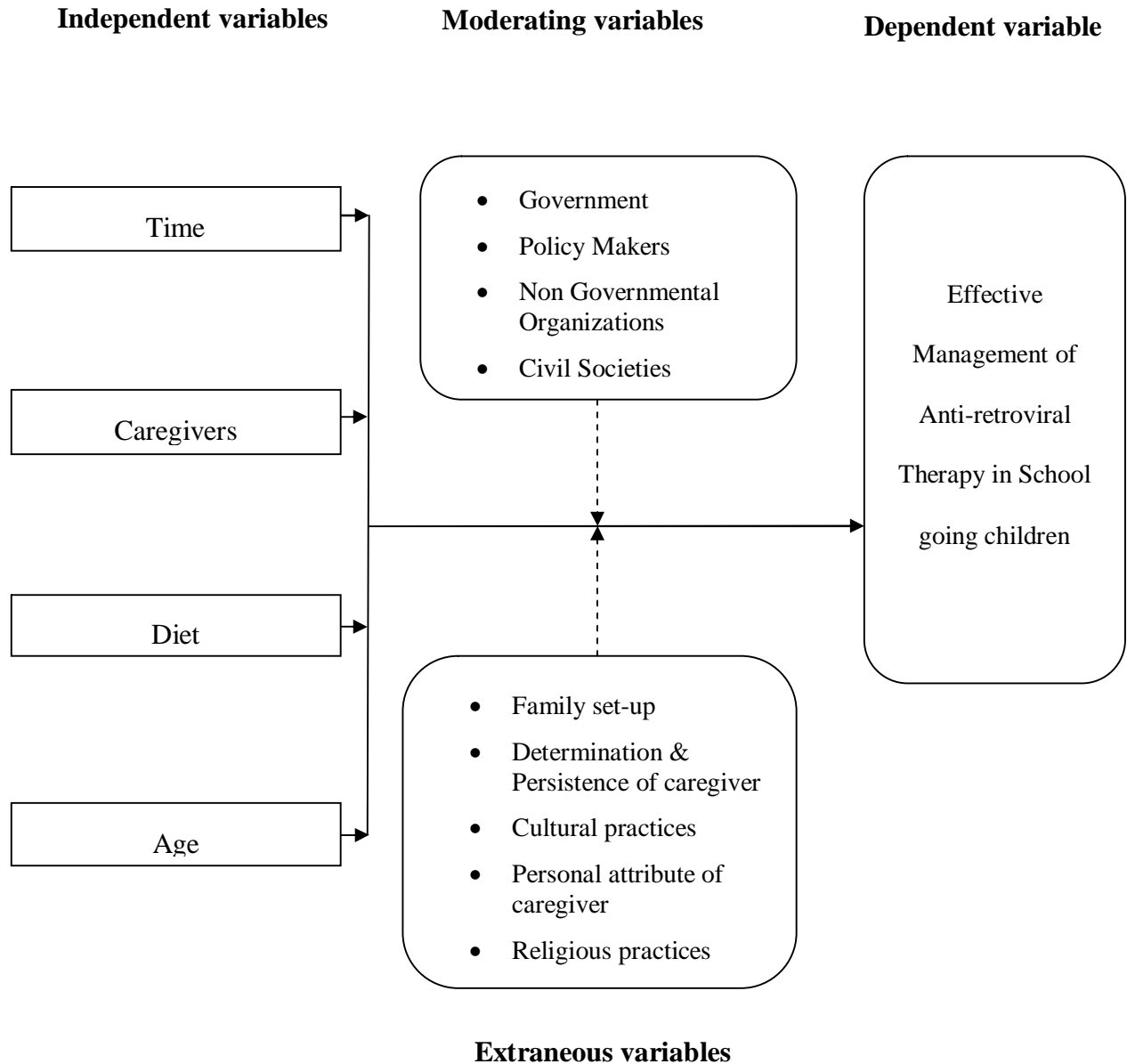
Research shows that students who graduate from boarding schools achieve greater career advancement than private day and public school students, and are more actively involved in philanthropic causes (Dieter, 2004). Boarding schools bestow on students an independence they would not have living at home. It's an ideal preparation for the challenges and responsibilities of adult life. In this study the researcher will uncover whether children undergoing ARVT attend boarding school.

Co-curricular activities are activities that students participate in that do not fall into the realm of normal curriculum of schools. They are found in all levels of our schools. There are many forms of co-curricular activities such as sports, clubs, governance, student newspaper, music, art, and drama. Co-curricular activities are totally voluntary so students that do not want to participate in them do not have to. Co-curricular activities serve the same goals and functions as the required and elective courses in the curriculum. However, they provide experiences that are not included in formal courses of study. They allow students to apply the knowledge that they have learned in other classes and acquire concepts of democratic life (Miller and Zittman, 2010). Co-curricular activities have many positive effects on education. The positive effects that co-curricular activities have on students are behavior, better grades, school completion, positive aspects to become successful adults, and a social aspect.

There are a number of advantages of co-curricular activities that may encourage parents and guardians to allow their children in their participation: Students that participate in co-curricular activities have reduced behavior problems (Cluver, 2003). In sports, they show discipline in drills, practices, and routines. They have a responsibility to perform those tasks correctly, whether it is basketball or football plays, dance routines, or signals in baseball or any other sports and festivals. When students perform these things correctly they are rewarded for their good behavior and they take pride in their accomplishments. Because of the pride they achieve, they gain better self-respect, self-esteem, and self-confidence. Education world states that “Participation in school activities, especially athletics, leads to higher self-esteem and enhanced status among peers, which some argue is deterrent to antisocial behavior.” (Brown et al, 2000). By participating in co-curricular activities students learn lessons in leadership, teamwork, organization, analytical thinking, problem solving, time management, learning to juggle many tasks at once and it allows them to discover their talents; Students that are involved in co-curricular activities meet many new people. Each club or sport is different, so students meet different people in all different groups. By joining different ones they meet people with the same backgrounds they have and people they share interests with. Most times the people that students meet are students that they would never talk to or become friends with on a normal basis. In different co-curricular activities students learn about group work, and sometimes they end up having less conformity to gender stereotypes (Brown et al, 2010).

Co-curricular activities are a part of students' everyday life. They play important roles in student's lives. They have positive effects on student's lives by improving behavior, school performance, school completion, positive aspects to make successful adults, and social aspects. In Africa and Kenya as a nation, we have known of music festivals, various sports and other school competitions that school children engage in. Sometimes, these activities may require that they travel away from home and their schools and spend out more than one night out. With this kind of situation and bearing in mind the numerous advantages of co-curricular activities, the researcher wants to find out if children on ARVT go for such activities and other school social events requiring spending away from home and how then is the therapy administered to them (Brown et al, 2010).

## 2.7 Conceptual Framework



From the conceptual framework above, the independent variables are the various factors that influence the effective management of ARVT in school going children. These, however, need to be incorporated in the policy making by stakeholders involved as moderating variables for the successful implementation of ARVT management as the dependent variable.



### **2.3 Summary of Chapter Two**

This chapter discusses about the discovery of HIV and AIDS, the development and approvals of policies and structures to help in the fight of HIV and AIDS, statistics on infected children and adults. It also gives an overview of the success and access of ARVT. Highlights children and adolescents exposure to HIV infection and as the critical strategies to avert and address the epidemic. It goes ahead to highlight the risks and benefits of delayed and early treatment and the importance of optimal adherence. It has covered factors that influence the management of ARVT as time, caregivers, age of the child and nutritional requirements. It has also given information on factual figures of HIV infected children in Kenya and explained in detail the various independent and dependent variables that are relevant to this research study and finally provides the conceptual framework of the research study.

However, there are some gaps that have been identified by the researcher that have not been adequately covered by the literature in the various studies and researches reviewed. For instance, studies and recommendations on ARVT adherence gives information about the timing of giving the ARVs, when the child should begin the ARV treatment and clinical benefits of early treatment. Some of the conditions not covered and may impact on time and adherence include: Lack of disclosure by the caregiver about the child HIV status that may mean that only the caregiver will be the person to give the child the medication, inability of the caregiver to communicate back in case of any delays or communication challenges brought about by the busy schedule of the caregiver. Food security and its availability are not covered by the studies on diet and nutritional requirements for HIV positive children. But only covers the importance of balanced diet for such children. In the case of caregivers, the stressor is about their importance to extend their responsibilities to ensure ARVT adherence. Other personal attributes of the caregiver such as attitude, temperament, culture, religion and norms that may affect their functionality in giving the child the medication are not included. Studies on age of the child and ARVT recommend when to disclose about the child's HIV status and why they are being given medication and eligibility to commence the medication. Children that are impaired by any medical or physical conditions are not discussed under the age factor.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter describes the procedures that were followed in conducting the study. It outlines the research design, target population, sampling design, sample size, data collection instruments and data analysis methods. It gives the procedures that was undertaken to gather measure and analyze data. It presents in detail the characteristics of subjects and apparatus that the researcher used as well as the procedures that were followed in the whole process of the research.

The sample was made of both parents or caregivers and school going children on ARVT who were drawn from the described population hence being the units of analysis. Data collection was done through administration of structured questionnaires, interviews and secondary data

#### **3.2 Research Design**

This study employed a survey cross sectional descriptive research design. It is the type of research used to obtain data that can help determine specific characteristics of a group of people. It is an empirical inquiry that investigates a contemporary phenomenon within its real-life context (Yin, 2008). Survey research is an ideal methodology when a holistic, investigation is needed (Feagin et al, 2001).

Descriptive survey involves asking questions often in form of questionnaires or interviews to a group of individuals (Yin, 2008). Using questionnaires, the respondents indicate their written answers either in short explanations or “yes or no” answers, in interviews the researcher will solicit answers to a set of questions. This research adopted the cross sectional descriptive survey by use of both questionnaire and interviews to enable the researcher make an analysis of the challenges experienced in the management of ARVT in schooling children.

#### **3.3 Target Population**

Much research populations are simply too large to be studied in their entirety because it is such an expensive, time consuming and extensive exercise and therefore researchers identify and define an experimentally accessible population. A finite population contains a countable number

of sampling units (Feagin et al, 2001). The target population of this study was therefore Nyang'oma Health Facility, Nyang'oma Mission. It has a population of 1,500 registered clients accessing ARVT and made of one thousand adults and five hundred children.

### **3.4 Sampling Procedure and Sample Size**

A sample is a subset of the population being studied and it represents the larger population (Ruane, 2006). It is a research technique widely used in the social sciences as a way to gather information about a population without having to measure the entire population. In this study the researcher adopted purposive sampling technique because the population of interest being investigated is quite small. The main goal of purposive sampling is to focus on particular characteristics of a population that are of interest, which will best enable the researcher to answer the research questions (Arghya, 2012). According to Kasomo (2008), Purposive sampling involves a selection of sample based on a certain purpose. In this study the purpose was to assess factors influencing antiretroviral management in school going children. This type of research increased the utility of research findings to the researcher. The researcher used the homogeneous purposive sampling technique because the samples have particular characteristics that are of interest to the researcher. Homogeneous Purposive sampling is a purposive sampling technique that aims to achieve a homogeneous sample, that is, a sample whose units (e.g., people, cases, etc.) share the same (or very similar) characteristics or trait (Cohen and Manion, 2009). The researcher selected sampling units based on her judgment of what units will facilitate the investigation.” (Adler and Clark, 2008).

In this study the researcher assessed “Factors influencing Management of Antiretroviral Therapy in School Going Children in Nyang'oma Health Facility, Bondo District, Siaya County. Purposive sampling may engross studying the entire population of a number of limited groups or a division of a given population (Engel & Schutt, 2009). The researcher considered it logical to confine herself to the support group discussions held on every Mondays, Tuesdays and Thursdays of the month to be the sample divisions. In this method it is assumed that the units are very similar in characteristics. It is approximated by the health facility that between 10 and 12 peoples both adults and children attend the support group discussions for each of the Mondays, Tuesdays and Thursdays.

The rule of thumb in determining the sample size is to obtain as big a sample size as possible. In adopting the homogeneous purposive sampling technique, the sample size included all the subjects who attended the support group discussions. According to Engel and Schutt 2009, 5% of any target population is adequate for the study. The sample size for this population will therefore be 72 units, 36 adults or caregivers who may be HIV positive or negative and 36 children who are undergoing ARVT. Those who refuse to take the interview were treated as non- return elements.

### **3.5 Research Instruments**

The type of data used in this study was primary data. Primary data provided valid information which met the objective of this study and filled the gap between what was known and what was not known.

The data collection instrument was questionnaires and interviews. When questionnaires are used well, they have an advantage in administration since a large number of respondents can be involved to provide information with an easy accumulation of data (Kombo and Tromp, 2010). Two questionnaires were used. The first questionnaire had questions for the schooling children undergoing ARVT, and are above ten years of age. The second questionnaire had questions for caregivers or parents for the school going children undergoing ARVT.

Interviews were used in the form of focus group discussions with the help of an interview guide semi structured questions. Key informants interviews were also used to interview some social workers and clinic staff. Secondary data was also used to get more information on the research topic.

### **3.6 Validity of the Research Instrument.**

According to Hessler, 2005 there are two basic goals in questionnaire design: to obtain information relevant to the purposes of the survey and to collect this information with maximal reliability and validity. The researcher made sure that the data gathering instrument that was used measured what it was supposed to measure and did this in a consistent manner by establishing validity. Validity can be defined as the degree to which a test measures what it is supposed to

measure. There are three basic approaches to the validity of tests and measures as shown by Anastasia, 2009. These are content validity, construct validity, and criterion-related validity.

Content validity measures the degree to which the test items represent the domain and the trait being measured (Hessler, 2005). In order to establish the content validity of the measuring instrument, the researcher identified the overall content to be represented. The researcher then randomly chose items from the content that accurately represented the information in all areas and obtained a group of items which was representative of the content of the trait to be measured. The researcher then used a panel of experts in the field to be studied to identify the content area. This study assessed factor influencing the management of ARVT in school going children. The researcher used a group made of a clinical officer, a social worker, HIV and AIDS expert and a caregiver who were requested to identify the content of the test or questionnaires that was developed.

According to Walter, 2010 the construct validity approach concerns the degree to which the test measures the construct it was designed to measure. In this study, the researcher ensured that the adequacy of the test in measuring the construct is evaluated. The researcher defined factors influencing the management of ARVT as those conditions or situations that affect the effective adherence of ARVT. A panel of experts was asked to evaluate these constructs. If the panel did not agree that the qualities pointed out by the researcher adequately defined the constructs, the researcher was to reformulate the previous definition of the construct and go through this process until it was agreed. The researcher then tested the adequacy of the test used by gathering data concerning the trait being measured and comparing it with from the test being assessed. If convergence exists, construct validity will be supported. After establishing convergence the researcher determined the discriminate validity of the test. This involved demonstrating that the construct can be differentiated from other constructs that may be somewhat similar. In other words, the researcher showed that the construct being measured was not the same as one that was measured under a different name.

Criterion-Related Validity approach is concerned with detecting the presence or absence of one or more criteria considered to represent traits or constructs of interest (Yin 2007). The researcher

tested for criterion-related validity by administering the instruments to a group that was known to exhibit the trait to be measured. The researcher developed a wide range of items for the test with invalid questions culled after the control group had taken the test, the culling process left only those items that were consistently measured the trait or construct being studied.

### **3.7 Reliability of the Research Instruments**

The reliability of a research instrument concerns the extent to which the instrument yields the same results on repeated trials (Yin, 2007). In scientific research, accuracy in measurement is of great importance. Scientific research normally measures physical attributes which can easily be assigned a precise value. The researcher used the retest method in which the same test (instrument) was given to the same people after a period of time. The reliability of the test (instrument) can be estimated by examining the consistency of the responses between the two tests. The researcher first visited two randomly chosen Nyangoma Health facility outlets , Wagusu and Nango, that were not part of the sample to pilot the research instruments. The sample size, data collection instruments and sampling techniques were put to test using the test retest method. Data analysis procedures were used to test the reliability of the research questions and amendments made subsequently.

### **3.8 Data Collection Procedures**

The researcher obtained authority from the University of Nairobi and the Medical Officer In charge of the health facility to conduct the study. In each of the visits the researcher introduced herself to the support group discussions using the respective letters of authorities. The researcher, after the introduction with the help of Nyang'oma Health Facility staff identified the support group discussions according to the described criterion. A consent letter and form was read out to the respondents to give them the chance to either agree or turn down the exercise.

Once the questionnaires were filled, the researcher waited for the next focus group discussions on another day, Monday, Tuesday or Thursday. This process was repeated until all the 72 respondents described in the sample size were been interviewed. Information collected was treated with high confidentiality.

### **3.9 Data Analysis Techniques**

Data analysis refers to the computation of certain measures along with searching for patterns of relationship that exists among data-groups. In the process of analysis, relationships or differences supporting or conflicting with original research questions or hypothesis should be subjected to statistical tests of significance to determine with what validity data can be said to indicate any conclusions.

In the quantitative data analysis the researcher used inferential statistics to measure how the independent and dependent variables interact among themselves. A partial correlation analysis was used to draw conclusions from data collected. Partial coefficient of correlation measures the effect of the independent variable on a particular dependent variable. The researcher used this type of analysis in order to measure separately the relationship between the variables in such a way that the effects of other related variables were eliminated. In this study, the researcher wanted to determine the relationship between the dependent variable, effective management of ARVT and each of the independent variables, time, adherence, diet and nutrition, caregivers and age of the child. The researcher drew conclusions according to the type of relationship that resulted from the analysis using SPSS version 20.

For the data collected from interviews, the researcher used qualitative data analysis by careful, in-depth recording of the opinions of the respondents of the research questions, through a naturalistic inquiry by the researcher and recording of respondent's quotes and discussions.

### 3.10 Operationalization Table of Variables

Objective	Variable	Indicator	Measurement Scale	Tools of Analysis
Factors Influencing ARVT Management in School going Children	<ul style="list-style-type: none"> <li>- Schooling</li> <li>- ARVT</li> </ul>	<ul style="list-style-type: none"> <li>- Clinical routine visits</li> <li>- Stigmatization</li> <li>- Absenteeism</li> <li>- Discrimination</li> <li>- Non participation in some co-curricular activities</li> <li>- Attending nearby schools</li> </ul>	Ordinal Ratios	Mean Standard deviation
Assess the challenges encountered by caregivers of school going children on ARVT	- Caregiver	<ul style="list-style-type: none"> <li>- Choice of livelihood</li> <li>- Short term or casual jobs</li> <li>- Economic burden</li> <li>- Clinical routine visits</li> <li>- Jobs closer home</li> </ul>	Ordinal	Mean Standard deviation Partial Correlation
Assess dietary requirements of children on ARVT	- Diet	<ul style="list-style-type: none"> <li>- Types of food</li> <li>-State of health</li> <li>- Frequency of eating</li> </ul>	Ordinal	Mean Standard deviation Partial Correlation
Assess which ages of the school going children on ARVT are vulnerable	- Age	<ul style="list-style-type: none"> <li>- Support for adherence</li> <li>- Distance of school</li> <li>- Type of school</li> <li>- Level of school</li> </ul>	Ordinal	Mean Standard deviation Partial Correlation



### **3.11 Ethical Considerations**

Ethical standards and values are very essential in any research work and design (Soitiros, 2005). This project therefore considered the following ethical views during the entire research.

Respect for potential and enrolled subjects: Respect of their privacy by managing information in accordance with the confidentiality rules and permitting subjects to change their minds and to withdraw from the research without penalties.

Informed consent: The purpose of informed consent is ensuring whether or not individuals enroll and participate in research only when it is consistent with their interests, values and preferences. Therefore the researcher accurately informed the respondents the purpose and methods of the research for them to make a voluntary decision whether to participate. In case of children, the research proxies in this case their caregivers chose the option that was in the best interest of the

## DATA ANALYSIS

### DATA ANALYSIS, PRESENTATION AND INTERPRETATION

#### 4.1 Introduction

This chapter is a presentation of the data analysis on the assessment of the factors influencing antiretroviral management among school going children the survey being at Nyang'oma Health Facility, Nyang'oma Mission in Siaya County.

#### 4.2 Response Rate

The total sample size targeted by the study was 72 respondents (36 adult care givers and 36 children undergoing ARVT). However, out of the 72 possible respondents, 30 (42%) care givers responded, 28 (39%) children responded. According to Yin, 2007 a response rate of 75% and above is recommended as good. Comparing with the total sample size, the response rate was 58 (80.6). Focus group discussions were also conducted using an interview guide through key informant interviews.

This response rate can be attributed to the data collection procedure, where the researcher visited the health facility during the times of support group meetings of the targeted population and conducting the data collection by herself, and clarifying questions from respondents before they indicate the responses. The 14 (19.6%) questionnaires that were not answered were brought about by inaccessibility of respondents to be interviewed in time and with various follow-ups there were no constructive responses from them. The response rate demonstrates willingness of the respondents' to partake in the survey.

**Table 4. 1: Response Rate**

	<b>Frequency</b>	<b>Percentage</b>
Care Givers	30	42
Children	28	39
None Return Elements	14	19
<b>Total</b>	<b>72</b>	<b>100</b>

### 4.3 Socio-demographic Information

This section covers the socio-demographic factors about the respondents of the research study. It gives information ranging from gender, age, educational level, household members and finally distance from the health facility.

**Table 4. 2: Gender of Care Givers**

	<b>Frequency</b>	<b>Percentage</b>
Male	6	20.0
Female	24	80.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Table 4.2 is a presentation of the care giver's gender and as depicted; majorities (80%) of the care giver respondents were female compared to their male counterparts (20%) who formed the minority of those who took part in the survey. The gender imparity is an indication that most of the care givers involved in caring for the affected children are women.

**Table 4. 3: Gender of Children**

	<b>Frequency</b>	<b>Percentage</b>
Male	8	28.6
Female	20	71.4
<b>Total</b>	<b>28</b>	<b>100</b>

Table 4.3 shows the gender of the children that took part in the study and as depicted; most of them were female (71.4%) while the male (28.6%) were fewer. The findings suggest that there are more girls than boys under ARV treatment in the survey that was conducted. This also means that more girls are infected with HIV than boys.

**Table 4. 4: Age Bracket of Care Givers**

	<b>Frequency</b>	<b>Percent</b>
18-30 years	10	33.3
31-40 years	10	33.3
41-50 years	6	20.0
Above 50 years	4	13.3
<b>Total</b>	<b>30</b>	<b>100.0</b>

Table 4.4 is a presentation of the age bracket of the care givers and as the study found out, majority (33.3%) of the care giver respondents were in the age bracket of 18-30 years and 31-40 years indicating that most the care givers are still within the active age of child caring and at the same time 20% of the care givers are between the ages of 41-50 years and finally only 13.3% of the care givers are above 50 years, indicating that we have old people as grandparents as caregivers. This goes further to indicate that parents to the children under the care of grandparents are already dead.

**Table 4. 5: Age Bracket of Children**

	<b>Frequency</b>	<b>Percent</b>
6-10 years	10	35.7
11-15 years	16	57.1
15-18 years	2	7.1
<b>Total</b>	<b>28</b>	<b>100.0</b>

The study sought further to identify the age bracket of the children under treatment and as in Table 4.5: majority (57.7%) of the respondents are between the age bracket 11-15 years followed by those in the age bracket of 6-10 years and finally those between the age bracket 15-18 years. The findings depict that most of the children are relatively young and are in primary school.

**Table 4. 6: Educational Level of Care Givers**

	<b>Frequency</b>	<b>Percent</b>
No education	4	13.3
Primary education	14	46.7
Secondary education	12	40.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

The study was also keen to identify the education level of the care givers and as in Table 4.6 most (46.7%) of the care givers have a primary education while 40% have a secondary education. There are also those who have no formal education making 13.3% of the total respondents. None of the respondents has tertiary education thus most of the respondents have basic education excluding those with none. These findings also indicate that most of these caregivers have no good income generating employment due to their education level that would earn them a good leaving to care for the children.

**Table 4. 7: Education Level of Children**

	<b>Frequency</b>	<b>Percent</b>
Pre-school education	6	21.4
Primary education	20	71.4
Secondary education	2	7.1
<b>Total</b>	<b>28</b>	<b>100.0</b>

Table 4.7 is a presentation of the educational level of the children under ARVT, a majority (71.4%) are in their primary education followed by those who are in pre-school (21.4%). Those respondents who are in secondary school had the least percentage of 7.1%. This findings also

meant that children under ARVT in secondary school are more aware of their HIV status and are shy to participate in such studies or were busy in school not to participate.

**Table 4. 8: Residence of Care Giver**

	<b>Frequency</b>	<b>Percent</b>
With Spouse	20	66.7
With other Siblings	2	6.7
With a Relative	2	6.7
Alone	2	6.7
Children	4	13.3
<b>Total</b>	<b>30</b>	<b>100.0</b>

Table 4.8 depicts who the care givers of the children under ARVT live with. Most of the care givers (66.7%) reside with their spouses while those residing with children were 13.3% .Care givers residing with siblings, relatives and those staying alone have 6.7%. The findings showed that most of the care givers would be assisted by their spouses in ARVT management of the children in case of their absence whereas those staying alone had a very difficult time managing ARVT in school going children.

**Table 4. 9: Residence of Children under ARVT**

	<b>Frequency</b>	<b>Percent</b>
Parent	12	42.9
Relative	10	35.7
Step-parent	2	7.1
Non Response	4	14.3
<b>Total</b>	<b>28</b>	<b>100.0</b>

Table 4.9 shows that most children under ARVT (42.9%) stay with their parents thus are privileged to have parental care. 35.7% of the respondents stay with their relatives thus extended family while those staying with step parents were 7.1%. it is indeed significant to note that 14.3% of the respondents did not respond to this question. This could mean that some of the children under ARVT live with caregivers that are neither their parents nor relatives and may

have not been in the position to know the kind of relationship or were afraid to say whom they live with.

#### 4.4: Assessment of the Success of Anti-Retroviral Therapy

The section below is a presentation of the findings based on a set of questions giving information on the assessment of the success of anti-retroviral therapy.

**Table 4. 10: Assessment of ARVT by Care Givers**

	<b>Mean</b>	<b>Std. Deviation</b>
Early ARVT in school going children leads to minimized health complications	5.0	0.0
Children who received support from family members during treatment tend to be healthier than those who did not	5.0	0.0
Antiretroviral therapy improves the quality of life of school going children	5.0	0.0
Stigma can affect children and they stop taking their ARVs	4.9	0.4
Care givers to children under ARVT choose to work near home in order to assist the child with the treatment	4.9	0.3
Care givers to children under ARVT prefer to choose a school nearby home for their children for better ARVT management	4.8	0.4
A balanced diet is key to a successful Anti-retroviral therapy in school going children	5.0	0.0
<b>Total Mean</b>	<b>4.9</b>	<b>0.1</b>

Table 4.10 is a presentation of the set of questions on the assessment of the success of anti-retroviral therapy. Early ARVT in school going children leading to minimized health complications had the highest mean (5.0) together with the suggestion that children who receive support from family members during treatment tend to be healthier than those who did not and also that antiretroviral therapy and good diet improves the quality of life of school going children

all having a mean of (5.0). This finding suggests that ARVT improves the lives of children in general.

**Table 4. 11: Assessment of ARVT by Children**

	<b>Mean</b>	<b>Std. Deviation</b>
Routine clinical visits has helped me to have good health in order to attend my schooling	5.0	0.0
Children who receive support from family members during treatment tend to be healthier than those who do not	4.9	0.3
Antiretroviral therapy improves quality of life of school going children	4.9	0.3
Stigma can affect children and they stop taking drugs	4.1	1.2
A balanced diet is key to a successful Anti-retroviral therapy in school going children	5.0	0.0
<b>Total Mean</b>	<b>4.78</b>	<b>0.4</b>

Table 4.11 is a depiction on the assessment of ARVT among the children under treatment. Routine clinical visits makes the child to have good health in order to attend schooling and that a balanced diet is key to successful ARVT in school going children both had the highest means of 5.0 (0.0) each while children who received support from family members during treatment tend to be healthier that those who did not and that ARVT improves the quality of life of school going children both having means of 4.9 (0.0).

#### **4.5 Time Management of ARVT in School Going Children**

This section is a presentation of the assessment on how ARVT is managed among school going children. The perspectives presented here are both for the caregivers as well as those of the children respondents who are under ARV treatment.



**Table 4. 12: Administration of ARVs**

	<b>Frequency</b>	<b>Percent</b>
At Home	50	86.2
Away from home	8	13.8
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.12 shows the findings on where the medication is administered. The results suggest that a majority (86.2%) of the respondents take the medication at home while (13.8%) do not have to take the medication at home giving reasons such as: the child may be travelling or the child may be held up at school. It also means that children do not carry their ARVs to be taken at school.

**Table 4. 13: Public Administration of ARVs**

	<b>Frequency</b>	<b>Percent</b>
Yes	38	65.5
No	20	34.5
<b>Total</b>	<b>58</b>	<b>100.0</b>

The respondents were asked on whether they would administer the medicine while other people are watching and a majority (65.5%) stated they would while only (34.5%) stated they would not. The (65.5%) who said yes reported that they would do so comfortable if they repackaged the medicine so that no one would know they are ARVs. A good number (34.5%) of the respondents are not in a position to feel comfortable taking medication in public and reported that they feared to be stigmatized.

**Table 4. 14: Failing to take ARVs at the Right Time**

	<b>Frequency</b>	<b>Percent</b>
Yes	12	20.7
No	46	79.3
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.14 is a reflection of the respondents views with regards to whether there is a time when a child misses his/her medication and most of the respondents suggested no (79.3%) while some stated that indeed medication can be missed (20.7%) citing reasons for missing medication such as: when medication is to be taken at home at a specific time, either the caregiver or child may be unavailable from home to give and take the medication and either the care giver or the child may forget to administer the medication for such reasons as coming late from the market or from doing house chores like fetching water, collecting firewood or being sent to the shop and playing with peers respectively.

**Table 4. 15: Type of Schooling**

	<b>Frequency</b>	<b>Percent</b>
Day scholar	53	94.6
Boarder	3	5.4
<b>Total</b>	<b>56</b>	<b>100.0</b>

Table 4.15 shows that most of the children under treatment are day scholars (94.6%) while only a small number 5.4% are boarders: for the day scholars' majority stated further that the school is very far from home while very few of them leave close to their schools. This finding suggests that most children under ARVT attend day school so that their caregivers can be in position to extend care reasonably under their own supervision.

**Table 4. 16: Participation in Co-curricular Activities**

	<b>Frequency</b>	<b>Percent</b>
Yes	24	41.4
No	34	58.6
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.16 is a depiction of whether the children under ARV treatment take part in co-curricular activities. A substantial number do not (58.6%) while on the other hand some take part (41.4%) and the extra-activities include: scouting and singing and sports within the school compounds.

**Table 4. 17: Participation in Co-curriculum Activities Away from Home/School**

	<b>Frequency</b>	<b>Percent</b>
Yes	6	10.3
No	50	86.2
Non-Response	2	3.4
<b>Total</b>	<b>58</b>	<b>100.0</b>

There are some children under treatment who take part in co-curriculum activities that require them to be away from home (10.3%) as shown in Table 4.18. During their stay away from home or school which ranges between 1-3 days, the children are not exempted from taking medication. Administration of the medicine is done either by the teacher in charge or by the child. Most caregivers reported that they were not comfortable with the child being away from home because either the teacher or the child would forget to take medication hence the children would not be allowed to participate in co-curricular activities taking them away from home and school for more than one day.

**Table 4. 18: Clinic Visits other than the appointment Date**

	<b>Frequency</b>	<b>Percent</b>
Yes	46	79.3
No	12	20.7
<b>Total</b>	<b>58</b>	<b>100.0</b>

Most of the children under treatment (79.3%) go to the clinic other than the appointment date for reasons including when the child falls sick or loses appetite all of a sudden. It was reported by the caregivers that this affects their school attendance. The location of the clinic in relation their home is considered by a majority of the respondents as being relatively far. The care givers also stated that they are comfortable to personally take their children under treatment to the clinic in order to give their health history since the last clinic visit.

**Table 4. 19: Assessment of ARVT Management in School Going Children (Care Givers)**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
When the child misses medication he/she is impacted negatively	4.9	0.5	0.023
Children who are infected have challenges in participating in co-curricular activities	4.9	0.5	0.019
The routine clinic visits are very important to the child to have an effective ARV therapy	4.9	0.3	0.011
Children who are under ARV therapy face stigma and discrimination from other students	4.7	0.5	0.018
It is advisable for children who are under the treatment to attend nearby schools avoiding boarding or far distance school	4.8	0.6	0.032
<b>Total Mean</b>	<b>4.8</b>	<b>0.5</b>	

Table 4.19 is an assessment of ARVT management in school going children from a care giver's perspective: when a child under treatment misses medication they are impacted negatively, children who are infected having challenges in participating in co-curricular activities and the clinical routines are very important in the child to have an effective ARVT having means of 4.9 (0.5), 4.9 (0.5) and 4.7 (0.5) respectively. It is advisable for children who are under treatment to attend nearby schools and avoiding boarding school had a mean of 4.8 (0.6) while children who are under ARVT facing stigma and discrimination from other students had a mean of 4.7 (0.5). Noting from the means, the response is on the upper quartile of 75% and over indicating a strong agreement since total mean is 4.8. From the P-values, the depicted trend is an indication of significance in relation to assessment of ARVT management since all the P-Values are less than 0.05.

**Table 4. 20: Assessment of ARVT Management in School Going Children (Children)**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
When I misses medication I am impacted negatively	4.8	0.4	0.036
Children who are infected have challenges in participating in co-curricular activities	4.2	1.1	0.018
The clinical routines are very important to the child to have an effective ARV therapy	4.8	0.5	0.00
Children who are under ARV therapy face stigma and discrimination from other students	4.7	0.5	0.026
It is advisable for children who are under the treatment to attend nearby schools avoiding far distance school	4.8	0.4	0.030
<b>Total Mean</b>	<b>4.7</b>	<b>0.6</b>	

Table 4.20 is the assessment of ARVT in school going children from the children perspective: when a child misses medication they are impacted negatively and it is advisable for children who are under the treatment to attend nearby schools avoiding far distance both having highest means of 4.8 (0.4). Clinical routines being very important to the child to have an effective ARV therapy had a mean of 4.8 (0.5) while on the other hand children who are under ARV therapy facing stigma and discrimination from other students having mean of 4.7 (.05) while children who are infected having challenges in participating in co-curricular activities having a mean of 4.2 (1.1). The total mean being 4.7 is an indication also of strong agreement and also the trend of the p-values show a clear and distinct significance in relation to ARVT assessment.

#### 4.6 Assessment of Choice of Livelihood by Care Givers

This section is a presentation of the assessment of the choice of the livelihood of the care givers to school going children on ARVT. The findings range from where the care givers work, what they do and its direct impact on the school going children under treatment.

**Table 4. 21: Care Giver working in the same Town/Centre as the school of the child**

	<b>Frequency</b>	<b>Percent</b>
Yes	42	72.4
No	6	10.3
Non Response	10	17.2
<b>Total</b>	<b>58</b>	<b>100.0</b>

The study in Table 4.22 sought to find out whether the care givers work in the same town as the children who are under their care: a majority (72.4%) stated yes while only 10.3% stated no. It is also significant to note that none response rate with regards to this question was at 17.2%. This findings depict that most caregivers took up work or employment that kept them closer too the children under ARVT that were under their care.

**Table 4. 22: Care giver being at Home to ensure medication is given to the children**

	<b>Frequency</b>	<b>Percent</b>
Yes	28	48.3
No	30	51.7
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.22 is a presentation of what the respondents suggested when asked if the care givers have to be at home when the medication is being given to the child. The findings suggest that a majority (51.7%) do not have to be at home in cases where the children were older and know exactly when and where to take the medication while those that have to be at home were 48.3% in the case for younger children who had started medication in the recent past and are not yet

acquainted with the routine for taking medication or younger children who must be reminded to take their medication.

**Table 4. 23: Medication given by another person other than Care Giver**

	<b>Frequency</b>	<b>Percent</b>
Yes	38	65.5
No	20	34.5
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.23 shows the response when the children and care givers were asked on whether someone else can administer the medication and a majority of them (65.5%) stated it being possible especially where close members like spouse and siblings to the child were aware of the child’s condition while 34.5% stated it as being impossible for the sake of keeping the child’s status confidential since in most cases it also meant that the caregiver would be the biological parent and of the child and knowing the status of the child would expose the status of the parents.

**Table 4. 24: Children under ARVT would undertake co-curriculum Activities that require them to be absent from home or school**

	<b>Frequency</b>	<b>Percent</b>
Yes	8	28.6
No	18	64.3
None-Response	2	7.1
<b>Total</b>	<b>28</b>	<b>100.0</b>

The caregivers and children respondents were asked whether they would take extra-curriculum activities that would require them to stay away from home and as shown in Table 4.25. Most of them stated no (64.3%) giving reasons such as they are not allowed by their care givers and sometimes their teachers to be away because they would forget to keep track of their doses.

**Table 4. 25: Caregivers would take up jobs that require them to be away from home on daily basis.**

	<b>Frequency</b>	<b>Percent</b>
Yes	12	40.0
No	18	60.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Table 4.25 assesses whether the care giver respondents would opt for jobs that would require them to be away from home and (40%) stated yes while the majority (60%) stated no citing reasons such as not wanting to leave the children alone to be cared for by somebody else and that it would be difficult for someone else to take care of the child and to give medication as prescribed and taking the child to the clinic for both routine visits and when it becomes necessary.

**Table 4. 26: Assessment on Choice of Livelihood by Caregivers**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
Sometimes I am called from work to attend to the child/children in cases of emergency	4.9	0.3	0.012
Source of livelihood is not enough to cater for all the needs of the affected child	4.9	0.3	0.046
Distance from workplace and home is a challenge faced when taking care of the infected child/children	4.6	0.8	0.032
I receive support from people who know that I have a child/children infected under my care.	4.6	0.6	0.010
I face stigma and discrimination from people who know I have an infected child/children under my care	4.6	0.8	0.00
<b>Total Mean</b>	<b>4.7</b>	<b>0.6</b>	



The Table 4.26 is a presentation on the choice of livelihood assessment from the care givers perspective: the point that sometimes the care giver is called from work to attend to child emergency case and the point that source of livelihood not enough to cater for all the needs of the affected children both had the highest means and standard deviations of 4.9 (0.3). The P-value trend on all the points shows significant levels in relation to ARVT assessment. The total mean is on the upper percentile of 75% thus strong levels of agreement with the statements.

**Table 4. 27: Assessment on Choice of Livelihood of Caregivers by Children**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
Sometimes I can be away from school in cases of emergency to visit the doctor	5.0	0.0	0.045
Source of livelihood for my care giver is not enough to cater for all my needs	3.9	1.5	0.012
Distance to school is a challenge faced by my care giver when taking care of me	3.8	1.5	0.00
My care giver receives support from people who know that I am infected and under ARVT.	4.9	0.3	0.00
I face stigma and discrimination from people who know I am infected and under ARVT.	3.6	1.7	0.03
<b>Total Mean</b>	<b>4.2</b>	<b>1.0</b>	

Table 4.28 is a depiction of the assessment on the choice of livelihood of the care givers from the perspective of the children under care. The children at times missing school because of emergencies to visit the clinic had the highest mean of 5.0 (0.0) followed by the opinion that the care givers receive support from people who know that the children are infected and are under ARV therapy having a mean of 4.9 (0.3). The responses that had the least means included the distance to school which is a challenge to care givers having a mean of 3.8 (1.5) while the response of facing discrimination from people who know they are infected had a mean of 3.6 (1.7). The total mean is on the upper quartile but less than 85% thus a relatively strong level of

agreement. The P-values which show the level of significance are also less than 0.05 thus a strong significance.

#### 4.7 Assessment of Diet Requirements for Children Under ARVT

This section is a depiction on the requirements of children who are under ARVT in terms of diet. The focus is on how livelihood is obtained and what kind of diet is given to the children who are under treatment.

**Table 4. 28: Source of Livelihood for House Hold**

	<b>Frequency</b>	<b>Percent</b>
Both farm and bought	48	82.8
Bought	10	17.2
Donation	0	0.0
Own Farm	0	0.0
<b>Total</b>	<b>58</b>	<b>100.0</b>

Table 4.28 is a depiction of the source of livelihood for the house hold where the respondents under treatment live: most of the food (82.8%) is from the farm and bought while some of them rely completely on bought food (17.2%). From the respondents that were interviewed, none rely on donations and own farm as the only source and means of livelihood. This findings also mean that most families have taken up the responsibility of caring for HIV persons by themselves rather than depending on outside well-wishers.

**Table 4. 29: Special Diet as a Requirement for ARVT Management**

	<b>Frequency</b>	<b>Percent</b>
Yes	42	72.4
No	16	27.6
<b>Total</b>	<b>58</b>	<b>100.0</b>

The Table 4.29 is a clear picture drawn from the respondents on whether they have requirements to take special diet and a majority (72.4%) stated that indeed they do take special diet while only 27.6% said no. These findings underscore the fact that the care givers have to have a stable source of livelihood in order to provide special diet for the school going children under treatment and that effective and efficient ARVT relies on special diet and good nutrition.

**Table 4. 30: Assessment on Choice of Diet Requirements (Care Givers)**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
The diet of children should be carefully watched and maintained	5.0	0.0	0.023
Loss of appetite is a major problem faced by the children under the ARVT	4.4	1.3	0.03
The source of food in my household is enough to sustain the dietary needs of the affected child/children	2.5	1.1	0.053
A balanced diet is essential for the child/children taking the drugs	5.0	0.0	0.012
Children taking ARVT who eat well are in a better state of health than those who eat poorly	5.0	0.0	0.048
<b>Total Mean</b>	<b>4.8</b>	<b>0.5</b>	

Table 4.30 is an assessment on the choice of dietary requirements by care givers: the diet of children should be carefully watched, a balanced diet being essential for the children under ARVT. Children who eat well are in a better state of health than those who eat poorly all had a mean of 5.0 (0.0). Loss of appetite being a major problem faced by children taking ARVT and source of food in the house hold being enough to sustain the dietary needs of the affected children had means of 4.4 (1.3) and 2.5 (1.1) respectively. The total mean is on the upper quartile of 75% while the p-values are all significant thus strong relations with ARVT assessment.

**Table 4. 31: Assessment of Choice of Diet Requirements (Children)**

	<b>Mean</b>	<b>Std. Deviation</b>	<b>P-Value</b>
The diet of children should be carefully watched and maintained	5.0	0.0	0.00
Loss of appetite is a major problem faced by the children taking the ARVT	3.8	1.4	0.011
The source of food in my household is enough to sustain the dietary needs of the affected child/children	4.3	1.1	0.056
A balanced diet is essential for the child/children taking the drugs	4.9	0.3	0.026
Children taking ARVT who eat well are in a better state of health than those who eat poorly	4.9	0.3	0.021
<b>Total Mean</b>	<b>4.6</b>	<b>0.6</b>	

Table 4.31 is a presentation of responses on dietary requirements from the children respondents' perspective. Children under treatment should be carefully watched and maintained had the highest mean of 5.0 (0.0) while a balanced diet is essential for the children taking drugs and children taking ARVT and children taking ARVT who eat well are in a better state of health than those who eat poorly both having means of 4.9(0.3). Loss of appetite being a major problem faced by the children under ARVs had the least mean of 3.8 (1.4). The total mean is at 4.6 indicating a strong agreement with the responses stated and finally the p-values are all below 0.05 thus implying significance in relation to ARVT assessment.

**CHAPTER FIVE**  
**SUMMARY OF FINDINGS, DISCUSSIONS, CONCLUSIONS AND**  
**RECOMMENDATIONS**

**5.1 Introduction**

This chapter presents the findings of the assessment on those factors that influence the management of antiretroviral therapy in school going children. In this chapter the researcher discusses the summary of findings according to the study objectives of time, caregivers, diet and age of the child, conclusions, recommendation and suggested areas for further study.

**5.2.1 Summary of findings on Time Management in ARVT**

The study found out that majority (86.2%) of the respondents prefer to take their medication at home and that (79.3%) of the respondents did not miss taking their medication. This study therefore found out clearly that most caregivers took into consideration the importance of administering the ARVs to the children at the right time and their good understanding of the implications that may result from taking the medication at the wrong time. Caregivers also preferred to have the children take medication at home since they used other modes of knowing the time of medication such as the wall clock as reminders. Medication is given to the children in the morning and evening and it is either administered by someone else (social worker or caregiver) or taken by the children themselves; the children are also able to take their medication quite regularly and on time due to the assistance of a wall clock, mobile phone alarm, during sunrise and sun set, when the shops open and close or through the radio news. The respondents incur costs while visiting the clinic, especially those who live very far away from; most of the time the caregivers and children under treatment walk to the clinic.

**5.2.2 Summary of Findings on Related Challenges face by Caregivers**

The study found out that most of the care givers (72.4%) work in the same town or centre where the children under their care go to school because they feel that they need to be close to them and take good care of them. Most of the care givers have to be at home to ensure that the medication is taken on time as the study found out that it is twice a day (morning and evening). Most of the care givers also stated that they would not opt for jobs that would take them away from home on

a daily basis. Some (10.3%) also stated that they would take jobs that would require them to be away from home on a daily basis since this would help them meet their daily financial needs of their families and that they had close relatives and family members who would take good care of the child. In case of any emergency, the care givers are called from work to attend to their children under treatment. Most of the care givers acknowledged that their source of livelihood is not enough to meet the needs of the affected children. The study also found out that most children (79.3%) would be taken for clinic visits other than the appointment date due to other arising complications and this needed the presence of the caregivers since they well understand the health history of the child.

### **5.2.3 Summary of Findings on Diet requirement of Children on ARVT**

Most of the food in the households that have children under treatment is both bought and comes from the farm (82.2%); there is no family that relies on donations. For children under treatment, special diet is a requirement (72.4%) while at the same time, a balanced diet is considered crucial and necessary since it was stated that children who take a balanced diet are healthier than those who do not take a balanced diet while under treatment. This study found out that those children who ate a balanced diet visited the clinic less frequent than those who faced nutritional problems.

### **5.2.4 Summary of Findings on Age of the Child and ARVT Management**

Most of the respondents in this study attended day school (94.6%) and those who lived far away from school said that the distance was quite long for them to cover while going to school and this many times made them take their medication late in the evening an; majority of the respondents are in primary school and pre-school living with their parents and relatives while some are living with their step parents. The study also found out that most (71.4%) children were in primary school and therefore needed more of the care and guidance of their caregivers. The children who receive support from family members have a healthier lifestyle than those who do not. ARVT was identified to be improving the lives of the children who are attending school.

Most of the children take their medication at home (86.2%) while at the same time the children under treatment comfortably take their medication publicly (65.5%) and others on the contrary feared to take medication in public. Children who miss medication are impacted negatively and routine clinic visits are very important and children who are under treatment are advised to avoid

distant schools. Most of the children (79.3%) attend clinic on other days other than the appointed day due to emergency and most of the time it is the care givers that take the children to the clinics.

Very few children under treatment (10.3%) attend extra-curriculum activities that require them to be away from school or home but a good number (41.4%) of the respondents participate in extra-curriculum activities such as scouting, singing and games within the school and do not require them to be away. Some of the reasons cited by the respondents for not attending activities that keep them away from school and home is that the care givers would not allow them and also that they would forget to take their medication. The student respondents who attend extra-curriculum activities either take the medication alone while away or the teacher in charge of the trip is responsible for the administration of the medication.

### **5.3 Discussion of the Findings**

This section discusses the key findings while at the same time comparing and contrasting with the literature review with respect to the study objectives. According to USAID/WHO (2006, 2007) the availability and regular use of ARV treatment has indeed made a positive impact to school going children under ARVT; this is agreement with the findings showing that indeed the respondents agree by stating that children who are under treatment are more healthier and live longer than those who are not.

The statistics according to the UNICEF (2012) show that 70,000-100,000 infants are exposed to HIV and Aids and the number has been predicted to be on the increase; the study got a response rate of about 84% thus showing a huge number of children who are HIV positive and are under treatment. The test for infants is currently conducted in clinics which provide immunizations states WHO (2010) thus in this study, the findings suggest that the children between the ages 6-18 years may have known their status and put under treatment from the local clinics that are available. Children under the age of two and are found to be HIV positive are put under treatment according to the WHO (2010) thus the long survival of the children in this study who are advancing from tertiary levels of learning to the primary and secondary levels.

The European Collaboration Study (2008) states that children who are under treatment spend more energy and are 7.5 kg lighter and 7.5 cm shorter at age 10 compared to those who are

uninfected; Crenn (2007) and Sheen (2008) argue that children under treatment should take more food and do less exercise. Comparing and contrasting with the findings, indeed the study found out that a balanced or special diet is important for these children to be healthy while the contrast is that the children participate in extra-curriculum activities which require more energy than that required by a child under treatment who does not participate in extra-curriculum activities.

USAID (2006) states that poor health in children under treatment is caused by poor appetite; the study findings confirmed the same since children who are under treatment at times lose their appetite and are not able to eat at all. Oneill et all (2003) argues that the early use of ARVs can indeed improve the health of children under treatment and the findings proved this since children in the facility started the treatment early and are living a healthy life and going to school as usual.

According to the Guardian (2009) it is recommended that ARVs should not be taken on an empty stomach or by children that are malnourished since this will have a negative effect and it is further recommended that children who are malnourished should first undergo nutritional therapy before being introduced to ARVT. The care givers in this study admitted that it is quite a challenge for them to provide food for the children since most of them are poor and do not have well-paying jobs to cater for the needs of the children who are under the treatment as indicated by the level of their education. Bechman (2010) states that providing food is by far a huge tussle thus making it even harder providing a balanced diet.

#### **5.4 Conclusions**

The partial correlation results for the study gave P-Values that were all significant thus showing that the independent variables are indeed related to the dependent variable making the study concrete and viable. The strong means leaning towards strong levels of agreement also draw out the clear picture of the study having relevant variables in real life situations for the children under ARVT.

ARVT has indeed proven successful in school going children and to some extent they are able to live normal lives facing minimal stigma amid other challenges the children face together with their caregivers. Children are able to attend school while at the same time involve in cocurricular activities and have their care givers to provide for them physical, psychological and emotional



support. The caregivers are very important for the success of ARVT in schooling children especially those children in pre-primary and primary level.

A balanced diet is essential to children under ARVT and so is the use of special diet since there are certain foods the children are not supposed to take as recommended by health practitioners; children have to be supervised to eat especially the young ones considering that at times they do not have the appetite to eat.

ARVT has become manageable since there are specific times that the drugs are taken and the children can follow up and remember using various means. Clinical routines on the other hand are also considered essential for regular checkups and to replenish their ARVs.

### **5.5 Recommendations**

After analysis and interpretation of this study, the researcher recommends on the following;

1. More sensitization should be done to care givers and teachers on the need for proper time management on ARVT, social support for caregivers of children on ARVT, a balanced diet of children on ARVT and caregivers educated on how to care for the children under treatment well since most of them have no education or low levels of education thus cannot read or write.
2. The Ministry of Health and the Ministry of Education should collaborate on ensuring that both primary and secondary schools have upgraded clinics that meet the demands of routine clinic visits of children under ARVT while in school so that their schooling and learning is not interfered with. Such clinics should have proper guiding and counseling programs and technical support for ensuring that children under ARVT are well taken care of while at school.
3. The Ministry of Health together with other research institutions should look into the possibilities of producing ARVs that do not require daily and frequent administration for people under ARVT in order to cope with some of the drug administration problems like the strict specific time adherence.

4. School heads should ensure that their catering units also cater for children that have conditions that require good diet and nutrition by specially providing for policies on how to care for such children through adequate diet and nutritional care.

### **5.6 Areas for Further Studies**

This research report suggests the following areas for further studies;

1. The role of male caregivers in the management of ARVT in children. The study found out that most of the caregivers were female and that male participation in caring for such children was minimal.
2. ARVT management of schooling children by single parents. The study found out that the children who were cared for well in terms of ARVT management lived with both of their parents since in the absence of one parent the other would take over the ARVT management of the child.
3. Factors influencing ARVT management in secondary school children. This study found out that most respondents of the study were primary school children who were directly under the care and guidance of their caregivers.

## REFERENCES

- African Journal of AIDS Research (2011). *10 (Supplement). Employment Discrimination and HIV Stigma (2011); Survey Results from the Civil Society Organizations and People Living with HIV in Africa.*
- African Press International (2009). *The Global Fund Report*
- AIDS Newsletter (1989). *AIDS in East Africa*
- Annastisa A. (2009). "*Psychosocial Testing.*" New York Macmillan
- Arghya R. (2012). "*The methodology of sampling and purposive sampling.*"
- Armstrong S. (2009), "*Caring for carers: Managing stress in those who care for people with HIV and AIDS,*" Switzerland: UNAIDS
- AMREF (2010). *Children and AIDS, Fifth Stocktaking Report*
- Barberi M (2009). *Cocurricular Activities.* New York,NY: St. Martin's Press
- Brown, M. D. (2000). *Science or soccer? "How important are cocurricular activities?"*
- Bechmann M, Booysen F. (2009). "*Health and Economic impacts of HIV/AIDS on South African households.*"
- Betterham M.J (2009). "*Investigating heterogeneity in Studies of resting energy expenditure in persons with HIV/AIDS: a meta analysis.*" American Journal of clinical nutrition 81(3)
- CDC HIV/AIDS Surveillance Report (2004). Vol. 16. Atlanta: *US Department of Health and Human Services*, CDC: 2005:1-46.
- Central Bureau of Statistics (CBS) [Kenya], *Ministry of Health (MOH) [Kenya], and ORC Macro.* 2004. Kenya
- Cherutich, P., et al., *Optimizing paediatric hiv care in kenya: Challenges in early infant diagnosis.* Bull World Health Organ, 2008.86 (2): p. 155-60.
- Cluver L. (2003). *The Psychological Well Being of AIDS Orphans in Cape Town, South Africa,* *Masters in Social Studies,* University of Oxford

- Cohen I and Marion L. (2009). *“Research Methods in Education.”*
- Collins D, Leibbrandt M. (2009), *“The financial impact of HIV/AIDS on poor household in South Africa:”* AIDS 2009 21 supplementary (Published Media)
- Consent Form (*Copy right 2012 The American Academy of Pediatrics*)
- Department of Health and Human Services (2009). *“HIV and its treatment: What you should know.”*
- Dunn A.M, Navara J.P, Stavolla J, J et al (2009). *“Adherence to Antiretroviral medication in HIV infected children: A collaborative approach with guidelines for care.”*
- Dybul M. Fausi A.S, Bartlett J.G, Kaplon J.E, Pau A.K (2008). *“Guidelines for using antiretroviral agents among HIV infected adults and adolescents”.*
- Demographic and Health Survey (2003). Calverton, Maryland” CBS, MOH and ORC Macro.
- Dieter, C. (2004). *From our mothers’ arms: The intergenerational impact of residential schools in Saskatchewan.* Toronto: United Church Publishing House.
- Dolata, Stephane and Keith N. Ross. *“ How Effective are HIV/AIDS Prevention Education Programmes?” IIEP Newsletter, Vol 28, no 3, September 2010*
- Engel J and Schutt R (2009). *“Fundamentals of Social Work.”*
- European Collaboration Study (2008). *“Height, Weight and Growth in children born to mothers with HIV infection in Europe.”*
- Feagin, J., Orum, A., & Sjoberg, G. (Eds.). (2001). *A case for case study.* Chapel Hill, NC: University of North Carolina Press.
- Ferrand . R . A, el a’, *Causes of Acute Hospitalization in Adolescence – February 2010*
- Government of Kenya, NATG (2004). *National Anti retroviral Treatment Guidelines,* National Department of Health.
- Green . p et al (2009). *“Hyperphagia contributes to the normal body composition and protein-energy balance in HIV infected asymptomatic men.”* Journal of Nutrition 134 (9)
- Heikens G.T et al (2008). *Are management of HIV infected severely malnourished children”.*

- HRSA (2009). “*Nutrition and HIV/AIDS*” *HRSA Care Action*. <http://aidsinfo.nih.gov/guidelines>
- Huni, Noreen M. (2009). “*Enhancing psychosocial support of children affected by HIV/AIDS: A special focus on memory work*”
- Hussler R. (2005). “*Social Research Methods Management*” *Publishing Company*, St, Paul: Los Angeles, New York
- Janet M. Ruane, (2006), *Essentials of Research methods, “A Guide to Social Science Research”*
- Jain V. Deeks S.G (2010). “*When to start Antiretroviral Therapy.*”
- JUNP HIV/AIDS (2010). *Global Report on the AIDS epidemic.*
- JUNP. HIV/AIDS (2010). *Joint United Nation Programme on HIV/AIDS; Outlook Report*, UNAIDS Geneva, July 2010
- Kelly, K., Freeman, M., Nkomo, N. & Ntlabati, P. (2009). “*The vicious circularity of mental health effects of HIV/AIDS: symptom and cause of poor responses to the epidemic. In: Møller, V. & Huschka, D. (eds.) Quality of Life and the Millennium Challenge: Advances in Quality-of-Life Studies, Theory and Research. Social Indicators Research Series 35, Springer*”.
- Kenya Demographic health Survey (2008).
- KNBS (2009). “*Kenya Demographic and Health Survey 2008-09 Preliminary Report.*” Calverton, Maryland.
- Kombo and Tromp, (2010), “*Proposal and Thesis Writing*”.
- Kasomo Daniel (2008). “*Research Methods in Humanities and education.*”
- Katherine L. (2010). “*A review of psychosocial support and the challenges faced caregivers in disclosing HIV positive status to children in Kibera.*” Unpublished thesis, SIT Graduate Institute, London
- Koeth, John R, MD et al (2010). “*Association between HIV/AIDS and energy intake.*”
- Kuo C, Operario D. (2009). “*Caring for AIDS-Orphaned children: A systematic review of studies on caregivers.*” *Vulnerable children and youth studies.*

- Larson R (2006). *Organized Activities as Contexts for Development; Cocurricular Activities, after School and Community Programmes*
- Link, B.G. & Phelan, J.C. (2009) *Conceptualizing stigma*. Annual Review of Sociology 27, pp. 363–385.
- Merson, M.H., O’Malley, J., Serwadda, D. & Apisuk, C. (2008). *The history and challenge of HIV prevention*. The Lancet 372(9637), pp. 475–488.
- Miller Sadker, D., & Zittleman, K. (2010). *The extra curriculum*. In *Teachers, schools, and society* (9th ed., pp. 189-190).
- Mellins C.A, Brakis-Cott. E, Richards A., Abrahams E, Nicholus S. (2009). “*Patterns of HIV status disclosure to peri-natally HIV infected children and subsequent mental health outcomes*”.
- Naar Kings S. Mentropiedro G, Nicholus S, et al (2009). “*Allocation of family responsibilities for illness management in pediatric HIV*”.
- National AIDS and STD Control Programme, Ministry of Health, Kenya. July 2008. Kenya AIDS Indicator Survey 2007: Preliminary Report. Nairobi, Kenya.
- National AIDS Control Council (NACC) and National AIDS and STD Control Programme (NASCOP) (2007).
- National Aids Control Council, Office of the President, Kenya (2008)
- Nicholas Blanchette, Mary Lou Smith, Susan King (2002); *Cognitive Development in School – Age Children with vertically Transmitted HIV Infection*.
- Nutrition and HIV/AIDS (2011). *A Trainign Manual of Nurses and Midwives*.
- Oneill JF, Selwyn PA, Schietinger H, eds. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. Washington, DC: U.S. Department of Health and Human Services; 2003
- Oburu P.O, Palnerus K. (2009), “*Parenting stress and self reported discipline strategies of Kenyan caregivers*”. International Journal of Behaviour Development

- Panel on Antiretroviral Guideline for Adults and Adolescents (2010). “*Guidelines for the use of antiretroviral agents in HIV infected adults and adolescents*”.
- Peter K. Quashie (2013). “*HIV Drug Resistance and the Advent of Integrase Inhibitors.*”
- Reddinton C, Cohen J, BadillohA. Et al (2010). “*Adherence to medication regimens among children with human immunodeficiency virus infection.*”
- Papola, P., Alvarez, M., & Cohen, H. J. (1994). *Developmental and service needs of school-age children with human immunodeficiency virus infection: A descriptive study. Pediatrics*, 94, 914–918. Reitan, R. M. (1969).
- Republic of Kenya (2005). *Ministry of Health: Guidelines for Anti Retroviral Drug Therapy in Kenya* 3rd Edition.
- Republic of Kenya (2011), *Analytical Report; 2005/6 Labour Force Survey. Central Bureau of Statistics. Ministry of Planning and National Development.* Government Printers.
- Rew L. *Sexual health promotion in adolescents with chronic health conditions.* *Fam. Community Health* 2006; 29:S61-S69.
- RPHA (2010). *Anti retroviral Treatment for HIV Infections in Infants and Children: Towards Universal Access: Recommendations for Public Health Approach 2010 Revision.*
- Sotirios Saratakos, (2005), *Social Reserch, 3rd Edition*
- Sprague, C. & Dickinson, D. (2008) *Introduction to the special issue: HIV/AIDS and the world of work.* *African Journal of AIDS Research (AJAR)* 7(3), pp. iii–vii.
- Scitoh A. Hull A.D. Franklin P, Spector S.A (2010). “*Myelomeningocele in an infant with intrauterine exposure to afavirenz*”.
- Sage.Beardsley T. (2009). “*Coping with HIVs Ethical Dilemmas*”.
- Thomson M.A et al (2012). “*Antiretroviral treatment of HIV infection*”. “*Recommendations of the international Antiretroviral Society – USA Panel*”.
- UNAIDS (2006) *AIDS epidemic update - special report on HIV/AIDS. December 2006, Geneva, Switzerland: UNAIDS (2006).* UNAIDS 2012. Global Report

- UNAIDS (2007). *Aids Epidemic Update*. UNAIDS, World Health Organization Geneva
- UNAIDS (2010). *Commission on HIV/AIDS and Governance in Africa; The Soci Economic Impact of HIV/AIDS*.
- UNAIDS (2012). *World Aids Day Report*
- UNAIDS/WHO (2004). *AIDS Epidemic Update: Geneva Switzerland*
- UNGASS (2008). *Country Report for Kenya, NACC Nairobi*
- Violari, A., et al., *Early antiretroviral therapy and mortality among hiv-infected infants*. N Engl J Med, 2008. 359 (21): p. 2233-44.
- WHO (1997) Fact Sheet N163
- WHO (1997). *WHO fact sheet N 163: Anti-retroviral treatment for HIV and AIDS WHO*.
- WHO (2007). *Nutritional Care of HIV Positive Children in Kenya, Malawi and Zambia; A Progress Report*.
- WHO (2009), *Antiretroviral Therapy of HIV infections in Children and Infants*.
- WHO and UNICEF (2010). *Policy Requirements for HIV Testing and Counseling of Infants and Young Children in Health Facilities, WHO and UNICEF, Geneva 2010*
- WHO, *Antiretroviral therapy for HIV infection in infants and children: Towards universal access. Recommendations for a public health approach. 2006, Geneva: World Health Organization*.
- Working Group on Antiretroviral Therapy and Medical Management of HIV infected children (2009). *“Guidelines for the use of Antiretroviral Agents in Pediatric HIV infection” PDF Department Health and Human Services*
- Walter R. B (2010). *“Educational Research”*. Longhorn, New York
- Wenke, C. (2010). *“Pathogenesis and consequences of HIV Associated wasting”*.
- WHO (2008). *“Consultation on Nutrition and HIV/AIDS in Africa, Lessons and recommendations for Africa.”*



WHO (2008). *“Consultation on Nutrition and HIV/AIDS in Africa: Evidence, Lessons and Recommendations for action”*.

WHO (2010). *“Antiretroviral therapy HIV infection in infants and children in resource limited setting:” towards universal access.*

WHO (2010). *“Nutritional requirement for people living with HIV/AIDS: Report of technical consultation”*.

Yin, R. K. (2008). *Case study research: Design and methods*. Newbury Park, CA:

Yin K. Robert (2009). *“Case Study Research: Design and Method Applied Social Research methods Series, Volume 12, Sage publications, Beverly Hill.*

Zachariah, R et al (2009). *“Risk factor for high early mortality patients o antiretroviral treatment in a rural district in Malawi”*.

## APPENDICES

### Appendix I: Letter of Transmittal

---

#### TO WHOM IT MAY CONCERN

#### **RE: INTRODUCTION LETTER- RESEARCH: DAUGHTY NIGHT EDITH**

The above named is a Post Graduate student at the School of Continuing Education at The University of Nairobi. In partial fulfillment of the requirements of the Master of Arts Degree in Project Planning and Management, I will be conducting a research on “**Factors Influencing the management of Antiretroviral Therapy in School Going Children – A case of Nyang’ma Health Facility**” for my research work. I request you to assist me with necessary information which forms an integral part of the research project. The information and data required is needed for academic purposes only and will be treated in **Strict-confidence**. Attached are the questionnaires I will be requesting to be filled. All information will be strictly kept confidential and will be used for purposes of the research study only.

Your participation and assistance will be highly appreciated and your co-operation will be highly appreciated.

**Daughty Edith Night**

**L50/68669/2011**

## **Appendix II: Children Consent Letter**

My name is \_\_\_\_\_ and I am from \_\_\_\_\_. I am conducting a research regarding challenges encountered by school going children who are on antiretroviral treatment. I would like to invite you to participate in the study.

### **What the Study is about:**

I am interested in finding out more about how schooling children deal with the antiretroviral treatment management and I want to understand the various challenges as a result of the treatment.

### **Permission to Participate:**

Since you are under 18, I would like to ask permission from you and your parent/guardian/caregiver who looks after you for your participation in a few sessions that have been planned for this study. I would like to talk to you at the times we both agree which do not disrupt your normal school co-curricular and co-curricular programme.

### **Voluntary Participation:**

Please understand that the choice is yours to participate or not in this study. However, we would like to hear your thoughts as a young person.

### **Your Privacy:**

We will be recording only one of your names and other details during our conversation, but you will not be identified by name in the report and I will make any every effort to keep what you say private

### **Risks and Benefits:**

While I do not believe that there will be any negative risks to participating in this study, however the information you share with us will most likely be of benefit to improving antiretroviral therapy through policy making and other research in future.

*(Copyright © 2012 by the American Academy of Pediatrics)*

### **Appendix III: Caregivers/Parents Consent Letter**

My name is \_\_\_\_\_ and I am from \_\_\_\_\_. I am conducting a research regarding challenges encountered by school going children who are on antiretroviral treatment. I would like to invite you to participate in the study as their caregivers.

#### **What the Study is about:**

I am interested in finding out more about how caregivers deal with the antiretroviral treatment management in schooling children and I want to understand the various challenges you face as a result of the treatment.

#### **Permission to Participate:**

I would like to ask for your permission as a parent/guardian/caregiver that looks after the child on antiretroviral therapy for your participation in a few sessions that have been planned for this study. I would like to talk to you at the times we both agree which do not disrupt your normal programme.

#### **Voluntary Participation:**

Please understand that the choice is yours to participate or not in this study. However, we would like to hear your thoughts as a caregiver.

#### **Your Privacy:**

We will be recording only one of your names and other details during our conversation, but you will not be identified by name in the report and we will make any every effort to keep what you say private

#### **Risks and Benefits:**

While I do not believe that there will be any negative risks to participating in this study, however the information you share with us will most likely be of benefit to improving antiretroviral therapy through policy making and other research in future.

*(Copyright © 2012 by the American Academy of Pediatrics)*

**Appendix IV: Consent Form**

I agree to participate in the study about the challenges encountered by schooling children who are on antiretroviral treatment. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop being involved at any point if I want to, and that this decision will not in any way affect me in a bad way.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

*(Copyright © 2012 by the American Academy of Pediatrics)*

## Appendix V: Questionnaire for Caregivers

Name of the interviewer:.....

Interview number:.....

Name of health facility .....

Date:.....

**NB:**

- Informed consent
- Subjects will be contacted at the support group discussions, where the interview will be conducted.

**Introduction of the interview, introduction of the study, consent requested with option not to participate and statement of confidentiality.**

### SECTION ONE: SOCIO - DEMOGRAPHIC INFORMATION

**[Please fill in the following details about yourself]**

a) Sex: M / F	
b) Age /Years	
c) Educational level	
d) Who do you live with? (spouse, children, mother etc.)	
e) What do you do for a living	
f) Distance from health facility (in time or distance)	

**SECTION TWO: ASSESSMENT OF ANTI-RETEROVIRAL THERAPY SUCCESS**

1. Please state the extent to which you agree or disagree with the following statements on the assessment of successive antiretroviral therapy in school going children. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree).**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Early ARVT in school going children leads to minimized immune system compromise or health complications					
Children who receive support from family members during treatment tend to be healthier than those who do not					
Antiretroviral therapy improves the quality of life of school going children					
Stigma can affect the children and they stop taking drugs					
Care givers to children under ARVT choose to work near home in order to assist the child with treatment					
Caregivers to children under ARVT prefer to choose a school nearby home for their children for better ARVT management					
A balanced diet is key to a successful Anti-retroviral therapy in school going children					

**SECTION THREE: ASSESSMENT OF THE ARVT MANAGEMENT ON SCHOOLING OF THE AFFECTED CHILDREN**

[Please give a brief explanation or tick your answer in the space provided]

1. What time does the child take the medication? .....
2. Who gives the child the medication? .....
3. Does the child have to take medication at home?            Yes [  ]            No [  ]
4. If no, where else does the child take the medication? .....
5. Can you give the child medication when people are seeing? Yes [  ]            No [  ]
6. Does the child perhaps miss taking the medication?            Yes [  ]            No [  ]

7. If yes, when what happens? Please explain.....  
 .....  
 .....  
 .....
8. What helps you give the child medication regularly? .....  
 .....  
 .....
9. Is the child a day- scholar or boarding student? .....
10. How far is the school from home? [Time or Distance] .....
11. Does the child participate in co-curricular activities? Yes [ ]            No [ ]
12. Does the child at times spend out from school/home to participate in co-curricular activities? Yes [ ]            No [ ]
13. If yes, what is the longest days can the child spend out? .....
14. Who gives the child medicine when she/he spends away from home/school?  
 .....  
 .....
15. How often is the child taken for routine clinic visits? .....
16. Is there any other time when you have to take the child to the clinic other than the appointment date? Yes [ ]            No [ ]
17. If yes, under what circumstances? .....



18. Please state the extent to which you agree or disagree with the following statements on the assessment of the ARV management on schooling of the affected children. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
When the child misses medication he/she is impacted negatively i.e becomes very sick					
Children who are infected have a challenge participating in co-curriculum activities.					
The clinical routines are very important is the child is to have an effective ARV therapy.					
Children who are under ARV therapy face stigma and discrimination from other students					
It is advisable for children who are under the treatment to attend nearby schools avoiding boarding or far distant schools					

**SECTION FOUR: ASSESSMENT OF CHOICE OF LIVELIHOOD BY CAREGIVERS**

**[Please give a brief explanation or tick once in the space provided]**

1. What do you do to earn a living? .....
2. Is your work contractual or permanent? .....
3. How far is your work place from your residence? [Distance or time].....
4. Do you work in the same town the child schools? Yes [ ]                      No [ ]
5. How many children do you care for that are under the ARVT? .....
6. Who gives the child/children the medication? .....
7. Do you have to be at home to give the medication to the child? Yes [ ]                      No [ ]
8. Can someone else give the child the medication apart from you? Yes [ ]                      No [ ]

9. Who takes the child for routine clinic visits? .....

10. Would you take up work that requires you to be away from home? Yes [ ] No [ ]

11. If no, why .....

Please state the extent to which you agree or disagree with the following statements on the assessment of choice of livelihood by caregivers. (1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)

[Please tick only once for each subject]

Subject Rating	1	2	3	4	5
Sometimes I am called form work to attend to the child/children in cases of emergency					
My source of livelihood is not enough to cater for all the needs of the affected child.					
Distance from workplace and home is a challenge I face while taking care of the infected child/children					
I receive support from people who know I have children/child infected under my care					
I face stigma and discrimination form people who know I have an infected child/children under my care					

### SECTION FIVE: ASSESSMENT OF DIET REQUIREMENT FOR CHILDREN UNDER ARVT

[Please give a brief explanation or tick your answer appropriately in the space provided]

1. What is the source of food for your household?

Own farm [ ] Bought [ ] Both farm and bought [ ] Donation [ ]

2. Does the child on ARVT require special food? Yes [ ] No [ ]

3. Which type of food do you prepare for the child? .....

.....  
 .....

4. Are there times when the child refuses food?    Yes [ ]                      No [ ]
5. If yes what do you do in such a case? .....
- .....
- .....
- .....
6. Is there any food that the child is not supposed to take? Yes [ ]                      No [ ]
7. If yes, which types of food.....
8. Please state the extent to which you agree or disagree with the following statements on the assessment of choice of diet requirement for children under ARVT. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
The diet of children under ARV treatment should be carefully watched and maintained					
Loss of appetite is a major problem faced by the children taking the ARVT					
The source of food in my house hold is enough to sustain the dietary needs of the affected child/children					
A balanced diet is essential for the children taking the drugs.					
Children taking the ARVT who eat well are in a better state of health than those who eat poorly.					

**SECTION SIX: COST CONSIDERATION**

**[Please give a brief explanation or tick your answer appropriately in the space provided]**

- 1. How much do you have to pay to cover your travel expenses when you visit the clinic?  
.....
- 2. Do you lose any income as a result of your coming to the clinic? Yes [ ] No [ ]
- 3. Do you incur any other costs as a result of taking your child to the clinic?  
Yes [ ] No [ ]
- 4. Does your family have to give anything up in order to be able to take the child for routine clinic visits? Yes [ ] No [ ]

**SECTION SEVEN: PERCEIVED PROBLEMS AND POSSIBLE SOLUTIONS**

**[Please give an explanation in the space below]**

- a. What do you perceive as the biggest problem regarding ARV treatment in school going children?  
.....  
.....  
.....  
.....
- b. What do you think could be done to improve this?  
.....  
.....  
.....  
.....
- c. Do you have any questions for me?  
.....  
.....

**THANK YOU FOR YOUR TIME AND CO-OPERATION!**

## Appendix VI: Questionnaire for Children

Name of the interviewer: .....

Interview number: .....

Name of health facility .....

Date: .....

### **NB:**

- Informed consent
- Subjects will be contacted at the support group discussions, where the interview will be conducted.

**Introduction of the interview, introduction of the study, consent requested with option not to participate and statement of confidentiality**

### **SECTION ONE: SOCIO - DEMOGRAPHIC INFORMATION**

**[Please fill in the following details about yourself]**

a) Sex: M / F	
b) Age /Years	
c) Educational level	
d) Who do you live with? (Parents, relatives, friends )	
e) Distance from facility (in time or distance)	

**SECTION TWO: ASSESSMENT OF ANTI-RETEROVIRAL THERAPY SUCCESS**

2. Please state the extent to which you agree or disagree with the following statements on the assessment of successive antiretroviral therapy in school going children. (1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)

[Please tick only once for each subject]

Subject Rating	1	2	3	4	5
Routine clinical visits has helped me to have good health in order to attend to my schooling					
Children who receive support from family members during treatment tend to be healthier that those who do not					
Antiretroviral therapy improves the quality of life of school going children					
Stigma can affect school going children and they stop taking drugs					
A balanced diet is key to a successful Anti-retroviral therapy in school going children					

**SECTION THREE: ASSESSMENT OF THE ARVT MANAGEMENT ON SCHOOLING OF THE AFFECTED CHILDREN**

[Please give a brief explanation or tick your answer appropriately in the space provided]

1. What time do you take the medication? .....
2. Who gives you the medication? .....
3. Do you go to take medication at home?            Yes [  ]            No [  ]
4. If no, where else do you take the medication? .....
5. Can you take the medication when people are seeing?    Yes [  ]            No [  ]
6. Do you perhaps miss taking the medication?            Yes [  ]            No [  ]
7. If yes, when what happens,? Please explain.....

8. What helps you take medication regularly? .....
9. Are you a day- scholar or boarding student? .....
10. How far is the school from home? [Time or Distance] .....
11. Do you participate in cocurricular activities?    Yes [  ]            No [  ]
12. Do you at times spend out from school/home to participate in cocurricular activities?  
       Yes [  ]            No [  ]
13. If yes, what are the longest days you spend out? .....
14. Who gives you medicine when you spend away from home/school? .....
15. How often are you taken for routine clinic visits? .....
16. Is there any other time when you have to go to the clinic other than the appointment date?  
       Yes [  ]            No [  ]
17. If yes, under what circumstances? .....
- .....
- .....



18. Please state the extent to which you agree or disagree with the following statements on the assessment of the ARV management on schooling of the affected children. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
When I miss the medication I am impacted negatively i.e becomes very sick					
Children who are infected have a challenge participating in co-curriculum activities.					
The clinical routines are very important in children to have an effective ARV therapy.					
Children who are under ARV therapy face stigma and discrimination from other students					
It is advisable for children who are under the treatment to attend nearby schools avoiding boarding or far distant schools					

**SECTION FOUR: ASSESSMENT OF CHOICE OF LIVELIHOOD BY CAREGIVERS**

**[Please give a brief explanation or tick your answer in the space provided]**

1. How does your care giver earn a living? .....
2. Is their work contractual or permanent? .....
3. How far is their work place from your residence? [Distance or time].....
4. Do they work in the same town you are schooling in? Yes [ ] No [ ]
5. How many children in your home are under the ARVT? .....
6. Who gives you all the medication? .....
7. Does your care giver have to be at home to give you the medication?  
Yes [ ] No [ ]

8. Can someone else give you the medication apart from your care giver?

Yes [ ]      No [ ]

9. Who takes you for routine clinic visit? .....

10. Would you go for extra curricula school activities that require you to be away from home? Yes [ ]      No [ ]

11. If no, why/ Please explain.....

.....  
 .....  
 .....

12. Please state the extent to which you agree or disagree with the following statements on the assessment of choice of livelihood by caregivers. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Sometimes I have to be away from school in cases of emergency to visit a doctor					
The source of livelihood for my care giver is not enough to cater for all my needs.					
Distance to school is a challenge faced by my caregiver while taking care of me					
My care giver receives support from people who know I am infected and am under ARVT					
I face stigma and discrimination from people who know I have been infected and am under ARVT					

**SECTION FIVE: ASSESSMENT OF DIET REQUIREMENT FOR CHILDREN UNDER  
ARVT**

**[Please give a brief explanation or tick your answer in the space provided]**

1. What is the source of food for your household?

Own farm [ ]      Bought [ ]      Both farm and bought [ ]      Donation [ ]

2. Do you require special food?      Yes [ ]      No [ ]

3. Which type of food do you eat? .....

.....  
.....

4. Are there times when you refuse food?      Yes [ ]      No [ ]

5. If yes what is done in such a case? .....

.....  
.....

6. Is there any food that you are not supposed to take? Yes [ ]      No [ ]

7. If yes, please explain.....

.....  
.....

8. Please state the extent to which you agree or disagree with the following statements on the assessment of choice of diet requirement for children under ARVT. **(1 is Strongly Disagree, 2 is Disagree, 3 is Neutral, 4 is Agree and 5 is Strongly Agree)**

[Please tick only once for each subject]

<b>Subject Rating</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
The diet of children under ARV treatment should be carefully watched and maintained					
Loss of appetite is a major problem faced by me taking the ARVT drugs					
The source of food in my house hold is enough to sustain the dietary needs of the affected child/children					
A balanced diet is essential for the children taking the drugs.					
Children taking the ARVT who eat well are in a better state of health than those who eat poorly.					

### **SECTION SIX: COST CONSIDERATION**

**[Please give a brief explanation or tick your answer appropriately in the space provided]**

1. How much does your caregiver pay to cover your travel expenses when you visit the clinic? .....
2. Does your caregiver lose any income as a result of your coming to the clinic?  
Yes [ ]      No [ ]
3. Do you incur any other costs, losses or challenges as a result of going to the clinic?  
Yes [ ]      No [ ]
4. Does your family have to give anything up in order to be able to take you for routine clinic visits? Yes [ ]      No [ ]

**SECTION SEVEN: PERCEIVED PROBLEMS AND POSSIBLE SOLUTIONS**

**[Please give a brief explanation in the space provided]**

- a. What do you perceive as the biggest problem regarding ARV treatment in school going children?

.....  
.....  
.....  
.....

- b. What do you think could be done to improve this?

.....  
.....  
.....  
.....

- c. Do you have any questions for me?

.....  
.....  
.....  
.....

**THANK YOU FOR YOUR TIME AND CO-OPERATION!**

## **Appendix VII: Interview Guide**

1. What are some of the factors that influence the management of ARVT?
2. What are the challenges faced in the administering of ARVT to school going children?
3. Why is a balanced diet so important to children under ARVT?
4. How is ARVT management an economic or social challenge?
5. What are the economic or social challenges faced?
6. How does (i) Cost and (ii) Distance affect the ARTV administration to school going children?
7. How do you balance work and ARVT management you give to your child/children?
8. Which type of school would you prefer that the child under ARVT attends?
9. What age of children under ARVT requires more support and guidance from the caregivers according to you?