FACTORS INFLUENCING THE UTILIZATION OF PAEDIATRIC ANTI RETROVIRAL THERAPY SERVICES, A CASE OF EMBU DISTRICT, KENYA

BY

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DECLARATION

This research project is my original work and has not been presented for a degree in any other University or Institution.

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This research project has been submitted for examination with my approval as University Supervisor.

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DEDICATION

To my ever loving parents, Susan and Henry for always being there and sharing all the happy and sad moments in my life, for always encouraging and putting me on the right path. To my friend Sammy, for all the support and prayers and to my son Ciel, you are a leader of tomorrow and I love you.

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TABLE OF CONTENT

Declaration ii
Dedication iii
Acknowledgement iv
List of Figures ix
List of Tables x
Abstract xiii

CHAPTER ONE: INTRODUCTION 1
1.1 Background of the Study 1
1.2 Statement of the Problem 5
1.3 Purpose of the Study 6
1.4 Objectives of the Study 6
1.5 Research Questions 6
1.6 Significance of the Study 6
1.7 Delimitation of the Study 7
1.8 Limitation of the Study 7
1.9 Assumption of the Study 7
1.10 Definition of Significant Terms 8
1.11 Organization of the Study 9

CHAPTER TWO:LITERATURE REVIEW 10
2.1 Introduction 10
2.2 Theoretical Framework 10
2.2.1 The Andersen Behavioral Model 10
2.2.2. The Suchman's Model 11
2.3 Individual Factors 12
2.3.1 Level of Education 13
2.3.2 Attitude of the Caregiver 15
2.4 Societal Factors 16
2.4.1 Alternative Medicine to ART 19

2.5 Health Care Delivery System 21
2.6 Conceptual Framework 23
2.7 Summary 25

CHAPTER THREE:RESEARCH METHODOLOGY 26
3.1 Introduction 26
3.2 Study Design 26
3.3 Target Population 26
3.4 Sampling Procedures 27
3.4.1 Sample Size 27
3.5 Methods of Data Collection 29
3.6 Validity of the data collection instrument 30
3.7 Reliability of the data collection instrument 30
3. 8 Methods of Data Analysis 31
3.9 Ethical Considerations 31
3.10 Operationalization of Variables 31
3.11 Operational Definition of Variables 32

CHAPTER FOUR:DATA ANALYSIS, PRESENTATION AND INTERPRETATION 34
4.1 Introduction 34
4.2 Response rate 34
4.3 Individual Factors 35
4.3.1 Distribution of respondents by gender 35
4.3.2 Age of the respondents 35
4.3.3 Relationship with HIV positive child 36
4.3.4 Number of HIV positive members 36
4.3.5 Source of income 37
4.3.6 Number of meals in a day 38
4.3.7 Level of Education 38
4.3.8 Use of ARV drugs 39

4.3.9 Source of ARV drugs 39
4.3.10 Follow-up of ART regimen 40
4.3.11 Importance of completing treatment 40
4.3.12 Information on Drugs side effects 40
4.3.13 Drugs side effects 40
4.3.14 Action taken after adverse effects 41
4.3.15 Ever been tested of HIV 41
4.3.16 Importance of child knowing HIV status 42
4.3.17 Opinion on ART 42
4.3.18 Positive effect of ARV 43
4.3.19 Benefits of using ARVs 43
4.4 Societal Factors 44
4.4.1 Disclosure of child's HIV status 44
4.4.2 Avoidance of friends and relatives 44
4.4.3 Reminder to give ARVs 45
4.4.4 Importance of support group 45
4.4.5 Use of traditional/herbal medicine 46
4.5 Health Care Delivery System 46
4.5.1 Avoidance of visiting pediatric ART sites 46
4.5.2 Integrating CCC to outpatient services 47
4.5.3 Pediatric ART services waiting time 47
4.5.4 Medication refill challenges 48
4.6 Level of utilization of paediatric ART 48
4.7 Correlation analysis of dependent and independent variables 49
4.8 Qualitative Analysis 52
4.8.1 Responsibility and Blame 52
4.8.2 Experience surrounding stigma and discrimination 54

CHAPTER FIVE:SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATION 55
5.1 Introduction 55

4.3.9 Source of ARV drugs 39
4.3.10 Follow-up of ART regimen 40
4.3.11 Importance of completing treatment 40
4.3.12 Information on Drugs side effects 40
4.3.13 Drugs side effects 40
4.3.14 Action taken after adverse effects 41
4.3.15 Ever been tested of HIV 41
4.3.16 Importance of child knowing HIV status 42
4.3.17 Opinion on ART 42
4.3.18 Positive effect of ARV 43
4.3.19 Benefits of using ARVs 43
4.4 Societal Factors 44
4.4.1 Disclosure of child's HIV status 44
4.4.2 Avoidance of friends and relatives 44
4.4.3 Reminder to give ARVs 45
4.4.4 Importance of support group 45
4.4.5 Use of traditional/herbal medicine 46
4.5 Health Care Delivery System 46
4.5.1 Avoidance of visiting pediatric ART sites 46
4.5.2 Integrating CCC to outpatient services 47
4.5.3 Pediatric ART services waiting time 47
4.5.4 Medication refill challenges 48
4.6 Level of utilization of paediatric ART 48
4.7 Correlation analysis of dependent and independent variables 49
4.8 Qualitative Analysis 52
4.8.1 Responsibility and Blame 52
4.8.2 Experience surrounding stigma and discrimination 54

CHAPTER FIVE:SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATION 55
5.1 Introduction 55

5.2 Findings and Discussions 55
5.2.1 Objective 1 Individual factors and utilization of paediatric ART 55
5.2.2 Objective 2 Societal factors and utilization of paediatric ART 56
5.2.3 Objective 3 Health care delivery system and utilization of paediatric ART ... 56
5.3 Conclusions 57
5.4 Recommendations 57
5.5 Suggestion for Further Research 58
REFERENCES 59

APPENDICES 69
Appendix I: Letter of Transmittal 69
Appendix II: Questionnaire 70
Appendix III: Key Informant Interview Guide 75
Appendix IV: Focus Group Discussion Guide 77
Appendix V:Utilization of pediatric ART Services 79
Appendix VI:Research Permit 80

LIST OF FIGURES

Page

Figure 1:Conceptual Framework 24

LIST OF TABLES

Page

Table 3.1 Sampling matrix 29

Table 3.2 Operationalization of Variables 32

Table 4.1 Response rate 34

Table 4.2 Distribution of respondents by gender 35

Table 4.3 Age of the respondents 35

Table 4.4 Relationship with HIV positive child 36

Table 4.5 Number of HIV positive members 37

Table 4.6 Main source of income 37

Table 4.7 Number of meals in a day 38

Table 4.8 Level of Education 38

Table 4.9 Use of ARV drugs 39

Table 4.10 Source of ARV drugs 39

Table 4.11 Follow-up of ART regimen 40

Table 4.12 Information on importance of completing treatment 40

Table 4.13 Information on Drugs side effects 40

Table 4.14 Nursing drugs side effects 41

Table 4.15 Action taken after adverse effects 41

Table 4.16 Ever been tested of HIV 42

Table 4.17 Importance of child knowing HIV status 42

Table 4.18 Opinion on ART 43

Table 4.19 Positive effect of ARV 43

Table 4.20 Benefits of using ARVs 43

Table 4.21 Disclosure of child's HIV status 44

Table 4.22 Avoidance of friends and relatives 44

Table 4.23 Reminder to give ARVs 45

Table 4.24 Importance of support group 45

Table 4.25 Ever used traditional/herbal medicine 46

Table 4.26 Avoidance of visiting pediatric ART sites 46

Table 4.27 Integration of CCC to outpatient services 47

Table 4.28 Pediatric ART services waiting time 47

LIST OF TABLES

Page

Table 3.1 Sampling matrix 29
Table 3.2 Operationalization of Variables 32
Table 4.1 Response rate 34
Table 4.2 Distribution of respondents by gender 35
Table 4.3 Age of the respondents 35
Table 4.4 Relationship with HIV positive child 36
Table 4.5 Number of HIV positive members 37
Table 4.6 Main source of income 37
Table 4.7 Number of meals in a day 38
Table 4.8 Level of Education 38
Table 4.9 Use of ARV drugs 39
Table 4.10 Source of ARV drugs 39
Table 4.11 Follow-up of ART regimen 40
Table 4.12 Information on importance of completing treatment 40
Table 4.13 Information on Drugs side effects 40
Table 4.14 Nursing drugs side effects 41
Table 4.15 Action taken after adverse effects 41
Table 4.16 Ever been tested of HIV 42
Table 4.17 Importance of child knowing HIV status 42
Table 4.18 Opinion on ART 43
Table 4.19 Positive effect of ARV 43
Table 4.20 Benefits of using ARVs 43
Table 4.21 Disclosure of child's HIV status 44
Table 4.22 Avoidance of friends and relatives 44
Table 4.23 Reminder to give ARVs 45
Table 4.24 Importance of support group 45
Table 4.25 Ever used traditional/herbal medicine 46
Table 4.26 Avoidance of visiting pediatric ART sites 46
Table 4.27 Integration of CCC to outpatient services 47
Table 4.28 Pediatric ART services waiting time 47

Table 4.29 Medication refill challenges 48
Table 4.30 Level of utilization of paeditric ART 48
Table 4.31 Correlation between dependant and independent variables..... 50

Table 4.29 Medication refill challenges 48
Table 4.30 Level of utilization of paeditric ART 48
Table 4.31 Correlation between dependant and independent variables..... 50

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral (medicines)
AU	African Union
CCC	Comprehensive Care Clinic
CDC	Centre of Disease Control
FGD	Focus Group discussion
HIV	Human Immunodeficiency Virus
IDI	In Depth Interview
KAIS	Kenya AIDS Indicator Survey
KNASP	Kenya National AIDS Strategic Plan
MDG	Millennium Development Goals
MTCT	Mother-To-Child-Transmission
PLWHA	People Living with HIV/AIDS
THM	Traditional Herbal Medicine
UA	Universal Access
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's fund
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

ABSTRACT

Children's health, particularly in the early years, forms the basis of future health and development. Paediatric ART utilization and adherence is complex and current levels are often suboptimal. The purpose of this study was to establish the factors influencing the utilization of paediatric anti retroviral therapy services in Embu districts. The objectives of the study were to establish the extent to which the caregivers' individual or personal factors, societal factors and health care delivery systems influenced the utilization of pediatric ART services in Embu districts. This cross sectional study was carried out in Embu PGH, Kibuga HC, Nembure HC, Kangaru Dispensary, Karau HC, Itabua Dispensary, Kithimu HC, Kairuri HC, Runyenjes DH and Kianjakoma SDH. It employed a mixed mode approach which involved combining qualitative and quantitative methods of data collection. The study used three methods to collect primary data; focused group discussion (FGD), a survey using a questionnaire and in depth interviews (IDIs). Descriptive statistics was obtained including frequencies and percentages distribution by use of using SPSS version 18 software. Qualitative data was generally analyzed through a process of content analysis for themes. The findings were that transport cost and user fee for other medical services, use of herbal medicine, and stigma, lack of appropriate paediatric formulations, poor packaging and frequent stock outs influenced paediatric ART utilization. Many of these influences complicate measurement of pediatric ART utilization since there is no gold standard. It was concluded that the prevalence of utilization (74%), was sub-optimal (less than 95%) but comparable to those in other developing countries. Based on these findings, to enhance paediatric ART utilization the study recommends to the government and other stakeholders to develop strategies to ensure food security in households with children living with HIV and AIDS, Intensify health education campaigns against stigma and promote family and community support for children living with HIV and AIDS and ensure that all public health facilities have a adequate personnel and stock of paediatric ARV drugs.

CHAPTER ONE
INTRODUCTION

1.1 Background of the Study

Over 30 years after the Human Immunodeficiency Virus (HIV) was discovered, it remains a global health problem of unprecedented scope. UNAIDS estimates that 41 million people were living with HIV worldwide in 2003, 70 percent of whom were in Sub Saharan Africa (SSA) and 60 percent of whom were women, and infection rates were still on the rise. In 2004 UNICEF estimated that 20 million people around the world had died from AIDS, more than three-quarters of who were from SSA (UNAIDS/WHO, 2007).

Almost 3 million children under the age of 15 are estimated to have HIV worldwide, 90 percent of which are in SSA. In the developing countries approximately 1600 children are infected daily by HIV positive mothers (Pfund and Kerry, 2010). In 2002 there were 700 000 new pediatric infections in SSA and 580 000 pediatric HIV related deaths (this equates to 200 deaths per day, compared with 500 per year in United States or Europe). There is a 75 percent mortality rate by five years of age for children with HIV/AIDS in resource poor countries. In SSA AIDS is the cause of approximately 70 percent deaths in under fives. However, globally, AIDS accounts for 0.01 percent of mortality in this age group (Goldman et al, 2006).

According to UNAIDS 2007 Uganda report, the overall mortality rate for children under five is 137/1000 (Uganda AIDS Commission, 2007). Orphans account for 13 percent of all under 18 year olds (7 percent of the country's total population) and 20 percent of orphans have neither mother nor father (UNAIDS, UNICEF, USAID, 2004). Mother to child Transmission (MTCT) accounts for 21 percent of all HIV infection translating to 25 000 children per year are born HIV positive. 54 percent of children infected with HIV die before they reach the age of two (ANECCA, 1995) whereas median survival age in the West was 11 years, prior to the introduction of highly active antiretroviral therapy, HAART (Blanche et al, 1997).

Kenya has a generalized epidemic that is an epidemic that affects all segments of the society (NASCOP, 2008) and is a representative of many of the challenges Eastern and Southern Africa face in fighting the epidemic. More than 1.4 million people in Kenya are living with HIV with regional variation significant: prevalence remains high in Nyanza at 15.3%, more than double the national prevalence estimate (NASCOP, 2008). Other provinces with rates similar to or higher than the national level are Nairobi (9%), Coast (7.9%), and Rift Valley (7.0%). Prevalence in Eastern is 4.7% and in Central, 3.8% of the adult population is infected. North Eastern province has the lowest adult HIV prevalence at 1% (NASCOP, 2008). Data yielded an estimated national adult HIV prevalence of 5.1% in 2006, a reduction of 1.6% from 2003 (NACC Kenya, 2007). It indicated that national prevalence peaked at around 9% in 1997/1998. The current estimate of urban prevalence is about 8.3% and rural prevalence is 4.0% (NACC Kenya, 2007). The decline in prevalence since the late 1990s did not mean that the problem of HIV/AIDS was over. The number of people infected declined when the number of AIDS deaths exceeded the number of new infections (NACC Kenya, 2007). New infections occurred every day, especially among young people. In 2006 there were about 55,000 new adult infections (NACC Kenya, 2007).The vast majority of mass efforts to roll out Antiretroviral (ARV) drugs have concentrated on adults, not children yet children in Africa continue to die of AIDS at a high rate (Kippenberg, 2008).

Treatment scale up is having profound effects on HIV related mortality in many countries. Mortality rates of children born to HIV positive mothers are 3-10 times higher than for children born to HIV negative mothers (Boerma et al 1998).Some of the increased mortality of children of HIV positive mothers is due to Mother-to Child Transmission (MTCT) of HIV. Without any intervention, 13-48 percent of all newborn contracts HIV from their HIV infected mothers in utero, at birth or via breastfeeding (World Bank 1997). With efficacious interventions the risk of mother-to-child HIV transmission can be reduced to 2%. However, such interventions are still not widely accessible or available in most resource-limited countries where the burden of HIV is highest. The majority of children living with HIV can be served by timely administration of pediatric ART and Cotrimaxazole that has shown to have a positive impact on HIV

infected children survival. As a result of successful ART use, children are surviving into adolescence and struggling with many adherence challenges associated with long-term therapy (WHO, 2006). There is no cure for HIV/AIDS once the child has acquired it. Stunting, nutritional wasting, acute and chronic diarrhea, failure to thrive, pneumonia, thrush and neurological abnormalities are all associated with HIV infection in young children (Bailely et al 1999).

In the past decade, the international community has made concerted efforts to stem the HIV epidemic. In 2001, the UN member states adopted the Millennium Development Goals (MDGs), which set ambitious targets in the arena of health (United Nation, 2001). Goal 4 aims to reduce under five child mortality by two-thirds between 1990 and 2015, goal 6 aims to halt and begin to reverse the spread of HIV by 2015, and to achieve by 2010, universal access to treatment for HIV/AIDS for all those who need it (United Nations, 2001). The Global Fund to fight AIDS, Tuberculosis and Malaria prioritized access in Africa and concerted efforts to place the drugs within reach of ordinary populations. This was partly due to pressure from activist and people living with HIV/ AIDS (PLWHA), who demanded access to drugs in poor countries. On the regional level, the African Union (AU) has committed itself to fighting HIV/AIDS in the continent. In particularly, the Abuja call for accelerated Action towards Universal Access to HIV/AIDS, tuberculosis and Malaria services in Africa reiterates the importance of access to treatment (Abuja Declaration, 2001). However, the global roll-out of ARVs has largely focused on adults (Kippenberg, 2008). It was only until 2005 that a coalition of international actors come together to call for increased attention to treatment for children under the leadership of UNICEF, the "unite for children unite against AIDS" initiative was launched. The campaigned aimed to provide either antiretroviral treatment or Cotrimoxazole (antibiotic) or both to 80 percent of children living with HIV by 2010 (UNICEF/ UNAIDS, 2005).

In the past access to AIDS treatment in Africa was hindered by the sheer absence of ARV drugs or the enormous cost. Today, this has changed in many African countries, including Kenya and ART is now available for free (Kippenberg, 2008). Access of these drugs is a

question of life and death for children. Yet, too many children are still not accessing, for several reasons: foster parents may shun and exclude children living with HIV, physically abuse them, or refuse them food or medical care, even when the child is visibly sick, occasionally children who experience abuse may run away and become street children, which seriously reduces their chances of receiving HIV treatment, or are taken in by incomplete strangers (Kippenberg, 2008). Lack of accurate information about medical care for children is a critical problem. Many people are still unaware that effective and affordable medicine is available for HIV positive children, some people turn to traditional healers (Peterson, 2007). The stigma and guilt associated with the disease also remains a barrier to testing and treatment. Many children are not taken for testing because their caregivers worry the children will not keep the results secret, bring stigma on the family or revealing HIV positive status of adult members of the household (Foster et al, 2005). Access to healthcare for children is also hampered by transport cost and health related costs. For children over the age of five, caregivers have to pay for CD4 cell count, a test that assesses the child's immune function, as well as other medical tests and treatment of opportunistic infections (Kippenberg, 2008).

With the introduction of antiretroviral therapy, AIDS related mortality has declined. A study in Uganda found that timely initiation of ART and cotrimazaxole prophylaxis reduced mortality by 95 percent and also produced a 93 percent reduction in HIV related orphan hood (Mermin 2008a). In Botswana, where ART coverage exceeds 80 percent, the estimated annual AIDS related deaths has declined by more than half- from 15 500 in 2003 to 7 400 in 2007 while the estimated number of newly orphaned children has fallen by 40 percent (Stover, 2008). In Kenya AIDs related mortality deaths have fallen by 29 percent since 2002 (NACC and NASCOP, 2007). Important access gaps remain as more than half of all people in need of treatment are still not receiving such services. While Kenya was offering ART to roughly 190 000 adults in nearly 500 sites in mid 2007, only 12 percent of the estimated 1.4 million HIV infected persons were receiving the services (NASCOP, 2008).

It is against this background that the current study seeks to understand the environment in which infected children live. The environment denotes the protection practices of the parents or guardians, including the extend and depth of knowledge, awareness and attitudes towards pediatric HIV treatment, societal factors and health care delivery system that influence the utilization of pediatric ART services in order to design appropriate interventions that ensures improved care and protection of children and more specifically for vulnerable and HIV infected children.

1.2 Statement of the Problem

Children are disproportionate casualties of all sorts of disaster. The consequences of the global pandemic on Millions of children that live with their dying parents, or have been orphaned by AIDS or are living with HIV lie under the radar of most governments and agencies. It is estimated that 1.3million children under 15 years old in low and middle-income countries need antiretroviral therapy, only 28% of which were receiving treatment (UNAIDS, 2008). The immense surge of HIV mortality in children in the recent years means that it is now responsible for an estimated 300 000 child deaths annually in sub Saharan Africa and nearly 7 percent of all child deaths in the region. In 2007, of the 100,000 children who were HIV positive, 23,000 needed ART but only 13,000 children were receiving it. This was because of poor awareness on the part of parents and caregivers than non-availability of drugs (NACC Kenya, 2007). The HIV Incidence spectrum model, estimated that 34 000 children are infected with HIV in Kenya annually (NASCOP, 2008)). Some 150 000 children in Kenya infected with HIV; 60 000 of them need ART, about one-third of them-20 000 children are currently getting treatment while 40 000 are without access and will soon die if they do not get the drugs (Human Rights Watch, 2008). To achieve effective treatment and realize the benefits of treatment, strict adherence to treatment instructions are very critical. Sticking to the treatment instructions for a long term illness poses a great challenge to the patients (WHO, 2004). Just having medicine available cannot solve the HIV and AIDS problems. Worldwide, regardless of the illness or treatment many people do not take their medications correctly. Pediatric ART services is key to ensuring improved health in children living with HIV and that child mortality ratio is reduced by two-thirds by 2015

as stipulated in the fourth MDG and reduction of HIV related mortality by 25 percent and reduction of HIV related morbidity (NACC Kenya, 2009). Important access gaps remain as more than half of all people in need of treatment are still not receiving such services. While Kenya was offering ART to roughly 190 000 adults in nearly 500 sites in mid 2007, only 12 percent of the estimated 1.4 million HIV infected persons were receiving the services (NASCOP, 2008).This study will therefore assess the factors influencing the utilization of Pediatric ART services in Embu district.

1.3 Purpose of the Study

The purpose of this study was to assess the factors influencing the utilization of paediatric antiretroviral services in Embu district, Kenya.

1.4 Objectives of the Study

The objectives of the study were:

1. To establish the extent to which the parents/guardians' individual or personal factors influenced the utilization of pediatric ART services in Embu district.
2. To establish the extent to which societal factors influenced the utilization of pediatric ART services in Embu district.
3. To establish the extent to which health care delivery system influenced the utilization of pediatric ART services in Embu district.

1.5 Research Questions

1. How do the individual/personal factors of the parents/guardians influence the utilization of pediatric ART services?
2. Do societal factors influence the utilization of pediatric ART services?
3. How does the health care delivery system influence the utilization of pediatric ART services?

1.6 Significance of the Study

The findings of this study will be of invaluable use to Physicians treating HIV infected children and affected family members since they will be able to offer advice and referrals to parents/ guardians to assist in drug adherence, the social workers may have a better

insight into the issues faced by HIV positive children and their caretakers while coping with the disease, when planning for guardianship and custody of these children. Policy makers, Government of Kenya and stakeholders will use the findings to gauge whether the Pediatric ART services are achieving the desired effect or not. The government will use the insight provided by the study to improve in its shortcomings (if any) and to put measures in place to ensure that Pediatric ART services are fully utilized in order to achieve the desired goal which is improving the quality of health of children living with HIV and reducing child mortality in its commitment to ensuring the realization of the fourth and sixth MDG which are "reduce child mortality by two-thirds, and combat HIV/AIDS, malaria and other diseases." The results will also be of invaluable use to other multinational and international organizations whose work directly involves improving child health and reducing HIV related child mortality.

1.7 Delimitation of the Study

Participation in this study was delimited to parents/ guardians who lived with/cared for HIV positive children under the age of 16 years, in Embu district, and had been utilizing/not utilizing pediatric ART services. Other delimitation included high level of illiteracy among the caregivers which was overcome by conducting the interview in Kiswahili and Kiembu.

1.8 Limitation of the Study

The findings of this study cannot be generalized to other districts in the province. The findings are limited to Embu district. All the factors responsible for the utilization of ART services were not dealt with in this study. Psychological factors were almost ignored and the impact of health facility systems was only partially dealt with because the data was only collected from the beneficiaries, not from the medical personnel.

1.9 Assumption of the Study

The study took into consideration the assumption that variables used in the study were not change in the cause of the research period and that the respondents gave correct and valid information. It also assumed that the questionnaires issued were returned on time and dully completed.

1.10 Definition of Significant Terms

AIDS refers to a progressive immune deficiency caused by infection of CD4+ T cells with the human immunodeficiency virus (HIV).

Antiretroviral (ARVs) refers to the drugs used to minimize / reduce the viral load in an HIV infected individual.

Paediatric Antiretroviral therapy (ART) refers to the holistic care that encompassing ARV, adherence, nutrition and psychosocial support of HIV infected children.

Caregivers refer to the mothers/fathers/grandparents/ guardians of children with HIV who serve as parental figures for these children.

Child refers to a person under the age of 16 years.

Embu District Refers to Embu West, Embu North and Embu East districts

Individual factors refer to ones' characteristics which determine health seeking behavior.

Prevalence refers to 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.

Societal factors	refer to social, economic, cultural factors that determine health seeking behaviors.
Sub optimal utilization	Proportion of those using the services less than 95% of the time
Utilization	refers to the extent to which a given group uses a particular service in a specified period. Utilization will be used interchangeably with adherence.

1.11 Organization of the Study

Chapter one of this study introduced the problem statement and described the purpose, objectives, significance, basic assumptions, limitation and delimitation of the study.

Chapter two presents a review of literature and relevant research associated with the problem addressed in this study.

Chapter three presents the research methodology and procedures used for data collection and analysis.

Chapter four presents data presentation, analysis and interpretation.

Chapter five presents a summary and discussion of the study findings, conclusion, recommendations and suggestions for future research.

CHAPTER TWO
LITERATURE REVIEW

2.1 Introduction

This chapter presents the related literature on the study. Literature refers to any written previous work therefore it is the systematic review process of identification, location and analysis of documents containing information related to the research problem. The chapter hence presents a review of literature related to factors influencing the utilization of pediatric ART services.

The Areas covered in this literature review include: theoretical models which forms the basis of the conceptual framework and empirical studies that serves as a guide to better describe and examine the factors that influence parents/guardians' ability to utilize pediatric ART services. The literature review provides the reader with an explanation of the theoretical rationale of the problem of study as well as researches that have been done and how the findings relate to the problem. The purpose of this review is to avoid unnecessary or accidental duplication of materials already covered. This chapter therefore presents past studies, critical reviews, conceptual framework and summary of the literature review.

2.2 Theoretical Framework

There are many health care utilization models, but only two which have been widely used will be described and later modified to form the conceptual framework of this study. (See figure 1)

2.2.1 The Andersen Behavioral Model

Access to health care services is considered as the link between the health care system and the population it serves (Andersen, 1968; Aday and Andersen, 1974)). Utilization is proof of access or is evidence that access has been achieved (Fiedler, 1981). The volume and type of services, whether or not the service can be reached, the cost of the service, the client's perceptions of the relative worth of the service and the acceptability of services provided, all influence access and the utilization of services (Andersen, 1973;

Penchansky et al, 1981). Andersen's behavioral model of health services utilization was developed in 1968, to study factors that determine health care use. These are: individual factors, societal factors and health service system factors. Though it has undergone several modifications over the years, the behavioral model remains the most widely used in determining the utilization of health services (Kroeger, 1983).

The Andersen model has been used in many studies as theoretical or analytical framework to examine factors that determine the use of health services by several vulnerable populations, such as the disabled, the elderly, those with HIV/AIDS or other conditions (Hausmann- Mulea, 2003). The model proposes that people's use of healthcare services is a function of their predisposition to use services, the factors enabling or impeding use, their need for care, and their satisfaction with services. Studies have identified life-style, cultural or attitudinal factors, age and gender, as key factors affecting differences in the use of health services (Knutsen, 1994). In addition, factors influencing how symptoms and illness may be perceived, such as commonality of the disease, familiarity of the symptoms or clinical/physical changes, are partly responsible for health care seeking behavior (Jacobsen et al, 1995).

Andersen further described the individual factors as having three elements that relates to the individual's ability to utilize health services. These elements are: predisposing factors such as age, gender, formal education, religion, knowledge about the particular health issue; enabling factors include availability of services, socioeconomic status, social class, socio-support networks: Needs factors such as need for care, perception of illness, values and attitude towards health services. (Greene, 2005).

2.2.2. The Suchman's Model

The Suchman's model of socio-cultural and environmental determinants outlines critical determinants of health services utilization behavior as matters such as social networks of family and friends within which an individual finds himself , and also the 'lay referral systems' by which lay persons who are believed to be authoritative are approached before the professional physician(Suchman,1965). Therefore the level of knowledge of kin and

contact will be important in influencing utilization and it is noted that attitudes to illness and awareness of treatment vary considerably among cultural groups, low socio economic status, minority groups tending to be more isolated and to have lower factual levels of disease and treatment knowledge (Suchman, 1965). It has also be noted that a 'cosmopolitan' social structure is more likely to be related to a 'scientific' orientation to health and medicine whilst, a 'parochial' or traditional society is more likely to hold popular fold beliefs (Suchman, 1964).

2.3 Individual Factors

The utilization of health services can be viewed as a type of individual behavior. In general the behavioral sciences have attempted to explain individual behavior as a function of characteristics of the individual himself, characteristics of the environment in which he lives, and/or some interaction of these individual and societal forces (Moore, 1969).Individual factors include fear of disclosure and wanting to avoid taking medication in public places, feeling depressed, hopeless, or overwhelmed, having a concurrent addiction, forgetting to take medication at the specified time (Strace et al., 2002; Castro, 2005; Millis et al., 2006). Other barriers include being suspicious of treatment/medical establishment, wanting to be free of medication or preferring a natural approach (due to treatment fatigue); feeling that treatment is a reminder of HIV status, wanting to be in control, not understanding treatment instructions, still having doubt or not being able to accept HIV status and lack of self worth (Castro, 2005; Nakiyemba et al., 2005; Millis et al., 2006).

Some individuals have a propensity to use services more than other individuals, where propensity toward use can be predicted by individual characteristics which exist prior to the onset of specific episodes of illness People with certain of these characteristics are more likely to use health services even though the characteristics are not directly responsible for health service use. Such characteristics include demographic, social structural and attitudinal-belief variables. Age and sex, for example, among the demographic variables, are intimately related to health and illness.

2.3.1 Level of Education

Low level of education may impact negatively on some patient's ability to adhere, while high level of education has a positive impact (Catz et al., 1999; Nakiyemba et al., 2005). Belief about medication; there were eight reported barriers pertaining to beliefs/perceptions about medications: some common barriers in this category included: side effects (either real or anticipated), complicated regimens, and the taste, size, dosing frequency, and /or pill count. In other studies when individuals prescribed HAART felt healthy, adherence was often negatively affected (Castro, 2005; Millis et al., 2006).

Gupta et al (2007) cross sectional survey at six public and private sites to characterize the knowledge, attitudes, and practices (KAP) of ART among patients with HIV receiving care found out that of 1667 persons surveyed, 609 (36%) had heard of ART and 19% of these persons reported that ART could cure HIV. Twenty-four percent reported that they were currently taking ART, with 18% of these patients not actually on ART according to their provider. Major barriers to taking ART were cost (33%), lack of knowledge of ART (41%), and deferral by physician (30%). More than half of all public and private patients had not heard of CD4 (57%) or viral load testing (80%), and even fewer had received these tests (32% and 11%, respectively). Private clinic attendees were almost 4 times more likely to be on ART (35% versus 9%, $p < 0.0001$), more likely to be male, have a higher education, be partnered, have a higher income, and have had a CD4 or viral load ($p < 0.0001$). Overall, low levels of ART knowledge and access were observed among HIV infected patients, with access to ART being particularly low among patients attending public clinics

Knodel (2009) study in Thailand found that the respondents with low level of knowledge concerning ART were distinctly less likely than those with medium or high level to often remind the PLWHA to take ART medication and far more likely to rarely or never remind them to do so. Parents with low level of knowledge were also less likely than those with better knowledge to accompany PLWHA to obtain a re-supply of ART medication and far more likely to rarely or never do so, especially in comparison those with high level of knowledge. The relationship between knowledge level and the

frequency with which the parents reminded their adult children to go for re-supply is less clear, although those with low knowledge are less likely to usually do so than those with better knowledge.

In a study of factors affecting utilization of health care services by mothers of children ill with diarrhea in rural Vietnam, Hong et al identified maternal education as an important factor affecting the utilization of health care services. Mothers who completed junior high school and above were 1.40 times more likely to obtain treatment for their child than those who had not. These findings were consistent with another study investigating child health in Vietnam (Dominique *et al,* 1999), which indicated that ill children whose mothers were better educated were more likely to receive outside medical care. Higher educational levels have been associated with an increased self-perception of health status (Fernandez de la Hoz and Leon, 1996), and influence child survival and the use of both curative and preventative health care services (Cleland, 1989).

Hyera et al (2005) studied the HIV knowledge, attitudes and related behaviour and sources of knowledge among adolescent South Koreans. Their samples were drawn from schools that were conveniently selected and included (N=1077) high school students. The findings showed that the level of HIV/AIDS knowledge among Korean youths was moderate and that they exhibited a fairly negative attitude towards people with HIV. They observed that parents were a very insignificant source of information on HIV and that school lessons were a fairly important source of information. Knowledge from television was significant. Their recommendations were that HIV/AIDS interventions in schools could not only improve the level of knowledge it would also be consistent as it were.

A baseline survey on Children ART Literacy and pediatric treatment carried out in ward 8 and 17 of Murewa district, Zimbabwe in which Participants in the survey were drawn from a sample of 8 Support Groups, and included children living with HIV and AIDS, primary and secondary care-givers. The findings showed that children living with HIV are lacking the basic knowledge about HIV and AIDS and pediatric treatment, guardians

for children living with HIV/AIDS in most cases these are old grandparents whose general literacy levels are low. With the scenario is aggravated more so with medical terminologies and poor time keeping. The basic knowledge about HIV and AIDS pediatric treatment was greatly found wanting (Munyati and Gomo, 2006).

According to the KDHS (2008/9), knowledge and awareness of HIV and AIDS is nearly universal among all adults in Kenya (almost 100 percent). The only groups for which the level of awareness of AIDS falls below 98percent are women and men with no education and women in the lowest wealth quintile. The KDHS Behavior Surveillance Survey (BSS), found that over 70 percent of respondents of age group 15-49 years, had basic information on prevention and transmission of HIV but less than a third of the respondents knew about antiretroviral Therapy (KDHS, 2003).

While it is possible that better knowledge Promotes efforts that the parents make to provide treatment adherence support, it is also possible that the causality runs in the opposite direction. Thus, it may be that those who are more motivated and active in encouraging their adult children to adhere to the requirements of ART learn more about it as a result. Nevertheless, it seems plausible that the causality runs in both directions and that, better informed parents are more effective in providing treatment support than those who know little about ART.

2.3.2 Attitude of the Caregiver

In the first wave of the epidemic, an HIV diagnosis was a relatively quick death sentence, allowing for an approximated six months to live (Schiltz, Sandford 2000). Now, with earlier detection and a possibility of a less virulent strain of the virus, life expectancies of PLWHA have been extended. HIV changed from a quickly crippling disease to a chronic, manageable disease (Freedberg et al 1998).Starting 1996 new, more potent antiretroviral drugs became available, and triple combination of highly active antiretroviral therapy (HAART) was introduced (Pomerantz & Horn, 2003). This changed the way people looked at HIV/AIDS. Although these treatments are not a cure, they have dramatically reduced the rate of mortality and morbidity in developing countries.

According to KDHS 2009/8, four parameters where used to measure attitude; willingness to care for a relative with HIV at home, purchase of vegetables from a HIV positive vendor, believe that a HIV positive teacher should continue teaching and disclosure of a HIV positive family member status. The findings were the percentage expressing acceptance of all the four measures was low. Urban women are more likely than rural women to have accepting attitudes on all the four measures.

2.4 Societal Factors

A person's ability to seek health care is shaped by several factors including socio cultural, socio-economic, social networks and religious norms. These factors may hinder access to health services. (Jones, 2004). Stigma is a recognized problem for effective prevention, treatment, and care of HIV/AIDS. There is considerable literature indicating that stigma associated with HIV positive disclosure is a barrier to accessing ART by those needing it (Posse et al., 2008). It is a common place that social stigma attaches to people with HIV disease, those who are affected by HIV/AIDs and the programs which attempt to serve them (Gary, 1999). Stigma has been universally identified as a major concern to families and one which distinguishes the experience of pediatric HIV infection from that of any other diseases of childhood.

The availability of antiretroviral therapy (ART) and subsequent change in perception of HIV and AIDS as a manageable chronic disease has led to a decrease in stigma and discrimination in high income countries (Herek, et al, 2002). The situation is different in countries in Africa (UNAIDS, 2007) where ART has only recently become available to a large number of people. In several recent studies, people living with HIV and AIDS have still reported high stigma and discrimination experiences (Gilbert & Walker, 2009; Simbayi et al., 2007; Wolfe et al., 2006).

In both USA and Europe, studies have shown that families fear rejection and discrimination because of their HIV infection and hence keep the diagnosis to themselves. The very high degree of stigma associated with HIV infection and the notion

of shame makes it virtually impossible for parents to confide their diagnosis (Cohen et al.., 1995).

Logie and Gadalla (2009) conducted a meta-analysis on relationships between HIV-related stigma and a range of demographic, social, physical, and health characteristics in North America, and found high stigma level was consistently and significantly associated with lack of social support, poor physical health, poor mental health (including depression), lower age, and lower income. Smith et al (2008) found a negative, homogenous correlation between stigma and disclosure. Rao et al (2007) and Dlamini et al. (2009) have linked AIDS stigma to lower adherence to ART. There have been relatively few studies on the pathways of AIDS stigmas experienced by people living with HIV and AIDS. Pearson et al. (2009) found one year after initiating ART in Mozambique, participants reported no change in stigma, a decrease in perceived social support, and an increase in depressive symptoms. Kaai et al. (2007) found in a study cohort of people on ART in Mombasa, Kenya, that levels of internalized stigma decreased significantly after 12 months on treatment and social support remained high at follow-up.

Boulton et al 1999, in collaboration with pediatric clinic in a London teaching hospital study, the findings showed that on issue of disclosure, parents wanted few people as possible knowing about the diagnosis of their children. In issues of facing the future, parents accounted their concerns about death and dying and their anxieties about the future of the children. Of all the families in the study, the future threatened separation and loss although the nature of these losses varied according to families' circumstance.

Literature suggests that levels of expected stigmatization and discrimination materially affect self esteem and behavior of people living with HIV. Fife and Wright (2000) suggest that individual's perception of stigma account for the significant difference seen in the impact of an illness on the self. Perceived levels of stigma may also have a negative effect on willingness to present for Voluntary Counseling and Testing (VCT) and treatment.

Socio-economic Implications

In many African communities, the greatest impact of HIV/AIDS occurs at the household level. Although one member of the household could be HIV positive, the implication can be disastrous for an entire family. HIV and AIDs can impose extra expenditure on affected households for health care and funerals. Access to healthcare for children is also hampered by transport cost and health related costs. For children over the age of five, caregivers have to pay for CD4 cell count, a test that assesses the child's immune function, as well as other medical tests and treatment of opportunistic infections.

While the number of infected individuals and direct number of lives lost due to HIV/AIDS continue to grow, economic ramification of the virus become more severe. This is due in large part to the number of working age individuals afflicted with the disease (Evans & Becker, 2009). Since the virus disproportionately affects those in the prime years of their lives with respect to working and family responsibilities, economic losses and breakdown of family structures are products left in the wake of the epidemic (Skelton and Allan, 1999). Breakdown of family structures and the death of a breadwinner often results in children been neglected and abused and inadequate accessibility to basic needs. HIV/AIDS has led to an increase in the number of orphans globally and many HIV/AIDS sufferers have an added burden of looking after their infected children (Evans and Becker, 2009). Some of these HIV infected children have lost their parents and find themselves in the care of extended family, in particular grandparents .Children living their grandparents are potentially vulnerable since grandparents themselves are being "robbed" of their support mechanism, their sons and daughters, as AIDS epidemic spreads(Alden et al., 1991).

Antiretroviral therapy has been delivered free since early 2005 in Kenya, but the user bears the cost of medical support services and transport. These additional costs are often inseparable financial burden, which causes patients to default on their treatment. Adherence rate is high but still sub optimal (NACC Kenya, 2007).

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In Mombasa Kenya researchers from the Horizon Program and the International Center for Reproductive Health, in collaboration with Coast Province General Hospital conducted a study to find out how feasible Directly Administered Anti retro therapy would be in promoting adherence to ART (Sarna et al., 2005). They found out that despite challenges like time and resources involved in pre-packing the medication to ensure drug security, staff shortages and costs of providing transportation to poor clients, Directly Administered Antiretroviral Therapy had positive impact (Sarna et al., 2005).

2.4.1 Alternative Medicine to ART

Parallel to the traditional (western) medicine of HIV/AIDS, there are various alternative medicines or treatments available in different cultures (Standish, et al, 2002). In the USA, knowing that people with HIV/AIDS are going to alternative treatments, various studies are being made to understand the relationship between these treatments and HIV/AIDS. For example, the Federal Government of the United States has established the National Centre for Complementary and Alternative Medicine to deal with the issue of approaching scientifically the validity of alternative treatments. Non western medicine has various names such as alternative medicine, natural, or holistic, or complementary. Rather than using the word 'medicine' the word treatment is considered as a better word since some of the alternatives are not medicines. In 1992 the US Office of Alternative Medicine (OAM) categorized the field of Complementary and Alternative medicine (CAM) in to seven areas based on the providers (individuals), the substances and modalities used in the therapies (Standish, et al, 2002).

The Bastyr university AIDS research center in Seattle which was opened in October 1994, so far, has identified 1492 CAM therapies used for HIV/AIDS (Standish, et al, 2002). This center justifies the greater support for HIV/AIDS alternative medicine research as follows; There are many PLWHAs that are using these treatments but the scientific community knows very little about their safety and efficacy, some of the prescribed treatments are found to be harmful, the curiosity to look for further strategies for HIV/AIDS treatment since there is no cure till now, and the desire to see the interaction of alternative medicines and conventional anti-retroviral drugs, the demand to

do research on these areas and lastly some evidences show that a subset of alternative treatments may be effective and beneficial.

Feierman and Janzen (1992) have pointed out that a patient in the course of a single illness (could also be HIV/AIDS) might consult dispensary attendants, Christian or Muslim religious practitioners, medical doctors, specialists in sorcery cures, spirit-possession healers, herbalists, and others. They also indicated that the traditions of healing under each of the mentioned system evolve separately, each with its own logic and boundaries. They tried to distinguish, healing and therapy. Healing conceptions and rituals often try to address the eternal problems of the human conditions such as what is the nature of evil, of pollution, of danger, of the relationship between the living and the dead, or between people and spirit. But therapeutic practices are used, in most cases, to treat illness.

Ka'opua (1988) has tried to explain in broader sense the distinguishing characteristics of the non- western concept on disease and illness. Her explanation indicated that the nonwestern cultures conceptualize disease and illness from a more holistic perspective, which may include spiritual, emotional and social aspects. For example, for the traditional Hawaiians, health involves a balance of relationships between person, social system, physical environment, and the spiritual world. Being ill was not just a physical discomfort, but moreover an imbalance of spiritual or psychological wellbeing. So the diagnosis involved discovering the cause for the loss in balance in one or more of the key relationships and in healing those relationships.

In a small scale qualitative study (Boulton et al 1999) in collaboration with pediatric clinic in a London teaching hospital (which is a regional centre for care of children with HIV infection) on the experience of families with HIV infected children, an open ended, loosely structured interviews were carried out with parents and guardians of twenty two HIV infected children who were patients at the clinic. Topic discussed included day to day coping, relation within the family household, relationships with schools, friends and community, managing symptoms and promoting health, medicines and treatment and

concerns for the future. The findings showed that health and physical well being was of fundamental concern as children had progressed to the later stages of HIV disease and in the efforts to try and promote their health parents/guardians adjusted prescribed drugs and used other complementary or alternate medicines.

According to Langlois (2005), a cross-sectional study collected information on the behaviours and perceptions of HIV-infected adults in Kabarole district, Uganda, with respect to the use of traditional herbal medicine (THM) in the treatment of HIV/AIDS. Quantitative and qualitative data was gathered through the administration of semi-structured interviews (n=137) and group discussions (n=4) with persons living with HIV/AIDS (PLWHAs). Half of the study sample was composed of persons receiving antiretroviral therapy (ART). Additional information was collected from interviews with traditional healers (n=7). The findings indicated that THM use is widespread in PLWHAs regardless of the use of ART or gender. PLWHAs on ART also revealed high concurrent THM-ARV use. Despite the common use of THM and the potential for harmful herb-pharmaceutical drug interactions, there is minimal communication between PLWHAs and conventional medical practitioners about THM use.

2.5 Health Care Delivery System

To provide quality ART services, the health care system must have the necessary policies, infrastructure, supplies and human resources. The performance of health system in many countries has been affected by HIV/AIDS pandemic by increasing the demand for both quantity and quality of services and reducing the supply of services by its impact on the number and performance of health care providers (World Bank 1999; Bollinger 1999).

WHO 1994 report indicate that many governments in sub Saharan Africa place low priority on health and welfare as reflected in their national budget allocation for the heath sector; this contributes to lack of maintenance of health infrastructure, shortage of health workforce, supplies and drugs (WHO, 1994)

In a Kenya Health Worker Survey, carried out in 2005, health workers who participated in the survey expressed concern that health workers who do not have adequate training on HIV counseling and testing lacked confidence in themselves and may provide inadequate services to patients and miss important opportunities to inform patients of their HIV status. While understaffing is persistent problem throughout Kenya, Health care providers are bogged down by a myriad of challenges in their efforts to provide quality services such as; chronic shortage of personnel, limited health care infrastructure, lack of human capital development and institutional support, inadequate supplies and equipment (NASCOP, 2006).

Health care workers have fears of contracting HIV, which may affect their behavior and attitude towards the HIV infected client, leading to poor delivery of pediatric ART services. It is documented that health care providers fears and concerns of working with HIV positive patients due to the possibility of getting infected in their work place (RHM 2007).

In a study carried in four Asian countries on discrimination against HIV positive people, out of 764 men and women interviewed, 54 percent reported having experienced discrimination from health service provider. In Indonesia, the study found out that, women are twice as likely to experience discrimination as men. 15 percent of the respondents reported that they were refused treatment or care and 17 percent experienced delay in service provision. Another 9 percent were forced to pay additional charges due to their positive status (Cohen et al., 1995).

The effect that the clinic setting has on ART adherence should not be underestimated. Clinic characteristics that impact on adherence include: proximity to the patients home or place of work; the expense of getting there, lengthy delays between appointments, clinic opening and closing times, long waiting times, lack of services such as child care, privacy, confidentiality, and unsympathetic or inconsiderate staff (Nakiyemba et al., 2005).

2.6 Conceptual Framework

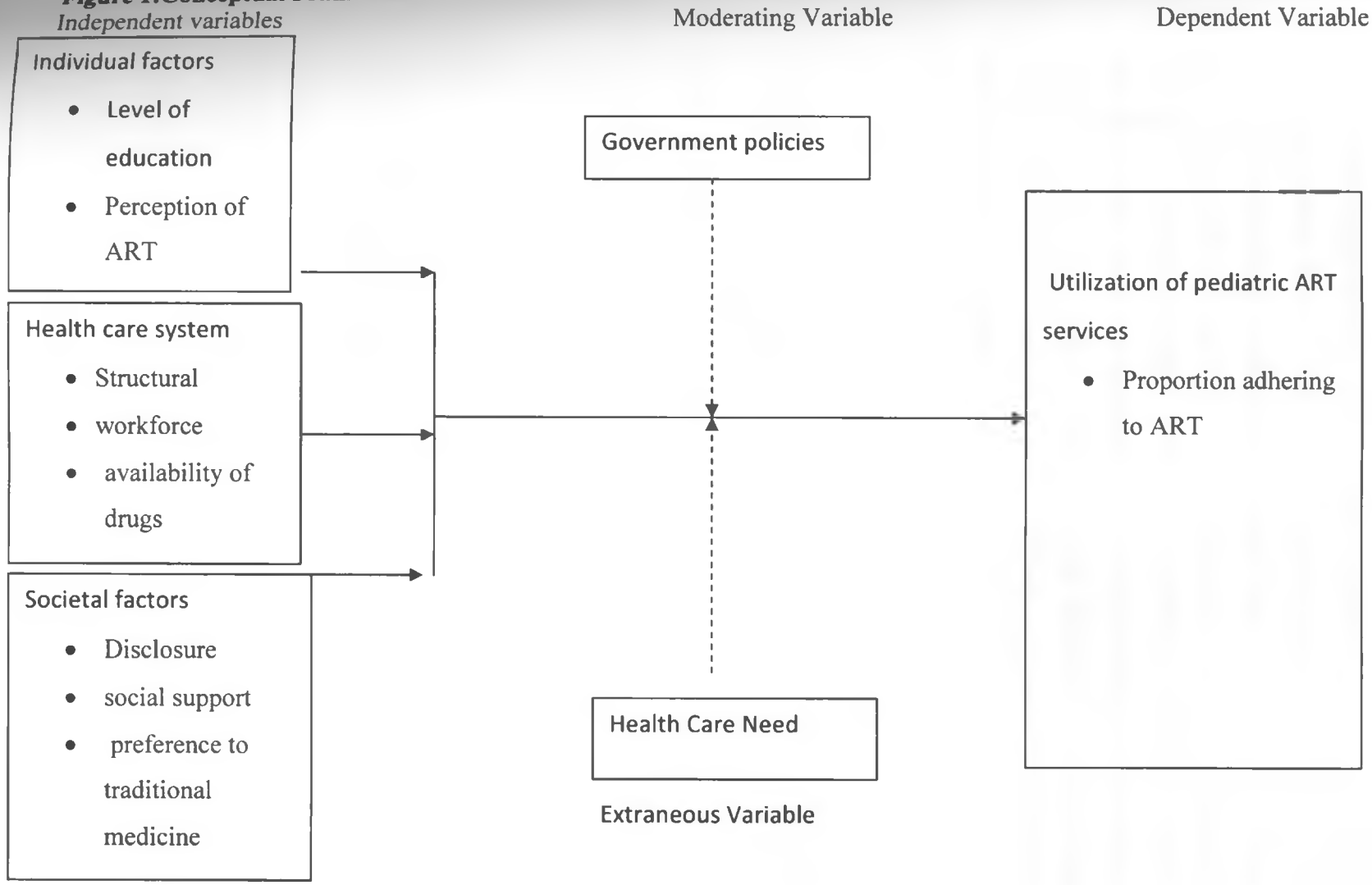
The modified model will be described under three main categories; individual factors, socio-cultural factors and health care system factors with selected variables, which may contribute to parent/ guardian ability to utilize pediatric ART services. These factors are:

2.6.1 Individual factors: Level of education, disclosure of child's HIV status, health belief attitude of the caregiver, Knowledge and perceived benefit of pediatric ART.

2.6.2 Societal Factors: Gender, stigma and discrimination, socio-economic, decision making processes, social support, alternative treatment.

2.6.3 Health care system: Structural, work force, availability of drugs, attitude of Health workers towards HIV positive clients

Figure 1:Conceptual Framework



2.7 Summary

The literature review indicates that most the researches carried out on HIV in Kenya as well as other developed and developing countries mainly focus on the adult population. The theoretical and empirical review outlines a number of factors have been identified as influencing health service utilization including ART. However, different communities in different geographical locations have a unique set of factors that are specific to that particular population. Children are vulnerable and their health care seeking behaviors are dependent on their guardians. Research is needed to determine parent/ guardian-important factors for utilizing paediatric ART in developing world settings. Clinicians should use this information to engage in open discussions with parents/guardians to promote paediatric ART use and adherence as well as to identify barriers and facilitators within their own populations.

CHAPTER THREE
RESEARCH METHODOLOGY

3.1 Introduction

This chapter looks in-depth on the research methodology that was employed by the researcher.

The content include the research design, target population, sampling procedure, methods of data collection, validity and reliability of the data instruments, operational definition of variables and last but not least the methods of data analysis.

3.2 Study Design

A cross-sectional study design was employed. The study design provided information about the presence and strength of associations between variables, permitting the testing of hypothesis about such associations. In the research, the qualitative and quantitative research paradigm was used. By doing so, techniques of triangulation of research methods were employed to generate data to address qualitative and quantitative issues (Kitchin and Tate 2000). Integrating both quantitative and qualitative data collection from multiple sources created a comprehensive picture of the multi-faceted factors influencing of pediatric ART services. Qualitative methods were valuable because they elicited salient issues that shed light on the social context of utilization of pediatric ART services. Qualitative research allowed the researcher to exercise judgment and do appraisal and interpretation of the interrelationships that reveal themselves as key determinants of pediatric ART seeking behaviors. Quantitative research used in the study provided statistical data which enabled comparison and analysis of information using statistical methods. The researcher used both quantitative and qualitative research methods in order to reduce bias.

3.3 Target Population

The primary study population for this research was that of parents/guardians with children living with HIV in Embu districts because their perspectives, knowledge and experience are essential to inform interventions and service delivery to improve

utilization practices. Some additional information was elicited from key informants. The KNBS (2009 vol 1c) estimates the number of children aged 0-16 years in Embu districts to be 10 984. The KDHS 2008-2009, estimates Eastern province HIV prevalence to be 3.5 %. The estimated population of children living with HIV in Embu district is therefore 3.5 % of 10 984 which is equal to 384. Out of this a sample of 81 guardians of children living with HIV were interviewed.

3.4 Sampling Procedures

Stratified sampling was used in which each government health facility in Embu district was a stratum. The respondents were then sampled from the ten strata. The sample size of each stratum was proportionate to the population size of the stratum. Simple random sampling procedure was used to sample any parent/ guardian arriving (with/without a child) and seeking Pediatric HIV services on a daily basis for the five clinic days in a week. Research assistants visited the hospital everyday of the five clinic days in a week for two weeks so as to neutralize the bias that might result if specific days are more preferred by parents/ guardians to attend the clinic. Purposive sampling was used to select the two main district hospitals (Embu PGH and Runyenjes DH) in the Embu district to participate in the FGDs. Two FGD were conducted with six participants each, a total of 12 respondents. However those who participated in the FGD were not eligible to participate in the questionnaire. 62 questionnaires were administered. 7 paediatric ART clinic in charges were interviewed for in depth interviews.

3.4.1 Sample Size

The sample was determined using following formula by Fisher et al (1998). The assumption was that the sample was to be representative; the sampling error was small, the sample wa viable in the context of funds available for the research study, systematic bias was controlle and results from the sample study will be generalizable in Embu district.

The total number of children aged 0-16 years in Embu district is 10 984(KNBS 2009 1c). Thi number exceeds 10,000. Therefore the sample size was obtained using a formula by Fisher et a (1998) for calculating sample sizes whose target population exceeds 10 000 persons as show below;

$$n = \frac{Z^2 pqD}{d^2}$$

Where; n= is the desired sample size when the study target population is over 10,000

Z - Is the normal deviate=1.96 which corresponds to 95% confidence interval.

P - Proportion of the target population estimated to have the desired characteristics.

Q= I – P

d = Degrees of freedom = 0.04

D - Is the design effect = 1 (since there will be no comparison between two study areas)

The proportion of the target population estimated to have the desired characteristics is 3.5%

Therefore;

P = 3.5/100 or 0.035

q = 1-p = 1- 0.035 = 0.965

Hence, the desired sample size (n) will be calculated as follows.

$$n = \frac{Z^2 pqD}{d^2} = \frac{1.96^2 \times 0.035 \times 0.965 \times 1}{(0.04)^2}$$

$$n = \frac{0.12975004}{0.0016}$$

n = 81.094 which is approximately 81

The formula used for obtaining the sample for each stratum is nh = (Nh / N) * n

Where nh is the sample size for stratum h, Nh is the population size for stratum h, N is total population size, and n is total sample size (Yamane 1967). Table 3.1 shows the sampling matrix for the target population

Table 3.1 Sampling matrix

Stratum (Health facility)	Population size (N)	Sample size (n)
Embu PGH	145	32
Kibuga HC	14	3
Nembure HC	18	4
Kangaru Dispensary	5	1
Karau HC	24	5
Itabua Dispensary	18	4
Kithimu HC	15	3
Kairuri HC	22	5
Runyenjes DH	72	16
Kianjakoma SDH	36	8
Total	369	81

Source: MOH 711

3.5 Methods of Data Collection

For the purpose of this study, the researcher utilized questionnaire, FGD, and in-depth, face-to-face interviews as method of data collection. According to De Vos (1998), the face-to-face interview assists researchers to understand the closed worlds of individuals, families, organisations, institutions and communities. FGDs was used because they make it possible to obtain information which is often concealed unveiling information about people's beliefs, attitudes and problems that is not likely to be obtained using other research techniques (Krueger 1988). The purpose of the in-depth, face-to-face interview is hence to understand the interviewee's life experience or situation as expressed in his/her own words (De Vos, 1998). Kruger (1988) further contends that the spoken interview allows participants to be as near as possible to their lived experience, does not preclude the possibility of dialogue during this early phase of research and does not involve the inhibiting effect of the process of writing on spontaneity of expression. The above purpose and advantages of in-depth interviews as method of data collection directly compliment the envisaged aim of this study, which is to explore and describe

primary caregivers' feelings and experiences in utilizing paediatric ART services in Embu district.

Data was collected in three successive stages; stage one involves data collection from FGDs. The researcher served as the moderator and one trained research assistants as a note taker. Two FGDs were conducted with six participants in each session giving a total of 12 respondents. In stage two, 62 questionnaires were administered. Respondents who had participated previous phases were not eligible for questionnaire. Finally, during stage three, 7 key informants were interviewed. Overall supervision was given by the researcher during the period of data collection. This exercise took two weeks.

3.6 Validity of the data collection instrument

Validity refers to the extent to which a questionnaire item actually measures what it purports to measure i.e. the extent to which it measures the underlying construct. Validity is the strength of our conclusions, inferences or propositions. Questionnaires and interviews were used as the instruments for data collection. To ensure validity of the instruments; a pilot study was conducted where ten randomly selected respondents were subjected to the questionnaire. To ensure that the data collection tools address the content validity, three key respondents were chosen to ensure that the contents were addressed.

3.7 Reliability of the data collection instrument

The reliability of a research instrument concerns the extent to which the instrument yields the same results on repeated trials. The tendency toward consistency found in repeated measurements is referred to as reliability (Carmines and Zeller, 1979). Reliability is the consistency of the measurement, or the degree to which an instrument measures the same way each time it is used under the same condition with the same subjects. The researcher used test/retest method. The questionnaire was administered to a selected sample of population and a test/retest carried out. This entailed administering the questionnaire at two separate times for each subject; the results of test 1 and test 2 were the same.

3. 8 Methods of Data Analysis

The quantitative data was entered and analyzed using Statistical Package for Social Sciences (SPSS) for windows. The deliverables of the data analysis were the frequencies of the various coded questions and correlations of variables under study. The outcome was presented in form of frequency and correlation analytical tables from which conclusions of findings and recommendations were drawn. Qualitative data was generally analyzed through a process content analysis for themes. The researcher reduced the text by marking individual interesting passages, which were then grouped into categories. The themes and categories that resulted from the data analysis and interpretation process were grouped into two fields of experience, namely: responsibility and blame, and stigma and discrimination.

3.9 Ethical Considerations

Permission to carry out this study was sought from the Ministry of Health. Informed consent was sought from all study participants. Confidentiality, anonymity and privacy were fully guaranteed.

3.10 Operationalization of Variables

Operational definition is a description of a variable, term or object in terms of the specific process or set of validation tests used to determine its presence and quantity. Operational definition of a variable is the description of the operation that was used in measuring the variable.

3.11 Operational Definition of Variables

Table 3.2 shows the operationalization of the independent and dependent variables that were used in the study.

Table 3.2 Operationalization of Variables

Variable	Indicators	Measurement scale	Types of analysis	Tools of analysis
Independent Variable. Individual factors	• Proportion of parents/guardians demonstrating knowledge in paediatric ART • Proportion of parents/guardians seeking medical services for adverse reactions. • Proportion of parents/guardians approving of paediatric ART	Ratio Nominal	Descriptive analysis Correlation analysis Qualitative analysis	Statistical Package for Social Sciences
Societal factors	• Proportion of parents/ guardians who have disclosed child's status. • Proportion of parents/ guardians enrolled in a support group • Proportion of parents /guardians preferring traditional medicines.	Ratio Nominal	Descriptive analysis. Correlation analysis. Qualitative analysis	Statistical Package for Social Sciences

Health care delivery system factors	• Proportion of parents /guardians comfortable with accessing ART in CCC. • Proportion of parents /guardians accessing refills ARVs in time. • Waiting time in clinic before been served.	Ratio Nominal	Descriptive analysis. Correlation analysis. Qualitative analysis	Statistical Package for Social Sciences
Dependent Variable. Utilization pediatric ART services	• Proportion of HIV positive children adhering to ART	Ratio	Descriptive analysis. Correlation analysis.	Statistical Package for Social Sciences.

Source: Author

CHAPTER FOUR
DATA ANALYSIS, PRESENTATION AND INTERPRETATION

4.1 Introduction

This chapter presents the results of the quantitative and qualitative findings. The section covers the following findings; the response rate of the study, demographic characteristics of the respondents, societal factors, individual factors and health system delivery factors. After data collection by use of questionnaires, data editing and data entry was carried out using Statistical Package for Social Sciences (SPSS). The data file was then cleaned for errors which could have emerged from wrong data entry. After cleaning, frequency and correlation tables were run. Qualitative data was generally analyzed through content analysis for themes.

4.2 Response rate

Table 4.1 presents the response rate of the study.

Table 4.1 Response rate

Stratum	**Number of responded that were to be interviewed**	**Number interviewed**
Embu PGH	32	30
Kibuga HC	3	3
Nembure HC	4	4
Kangaru Dispensary	1	1
Karua HC	5	4
Itabua Dispensary	4	4
Kithimu HC	3	3
Kairuri HC	5	5
Runyenjes DH	16	16
Kianjakoma SDH	8	7
Total	81	77

Out of a sample of 81 respondents, 77 were interviewed. Two FGDs of six participants each, 7 IDIs and 58 questionnaires were administered giving a response rate of 95.06%. According to Peil (1995), questionnaires return rate above 50% is considered good for a study.

4.3 Individual Factors

Individual factors were analyzed and presented as frequency and correlation tables.

4.3.1 Distribution of respondents by gender

Table 4.2 shows the distribution of the respondents by gender.

Table 4.2 Distribution of respondents by gender

Gender	Frequency	Percent
Male	9	15.5
Female	49	84.5
Total	58	100.0

The researcher was interested in knowing the gender of the respondents. KDHS 2008/09 indicates feminization of the epidemic with women bearing the greatest burden. The results in Table 4.2 below indicate that most of the respondents 84.5% were females as compared to males at 15.5%. It was observed that in every clinic appointments, although females were many compared to males, males were not willing to participate in the study hence the great difference between males and females who participated in the study. This then confirms KDHS 2008/09 survey on women bearing the greatest burden of HIV.

4.3.2 Age of the respondents

Table 4.3 shows the age of the respondents.

Table 4.3 Age of the respondents

Age	Frequency	Percent
17-≤ 30 Years	19	32.7
31-≤49 Years	28	48.3
50-≤ 60 years	11	19.0
Total	58	100.0

The respondents' age was between 17-60 years. Majority of the respondents were in the age group 17-49 indicating that the participants were within the reproductive age bracket (15-49).

The trend showed those seeking paediatric ART increased with increasing age and decreased as the age advanced beyond 50 years. From the IDIs, children who lived with their grandparents had difficulties in following the treatment regimen and more often missed clinic appointments. This suggests that the paediatric ART programmes should put more emphases on the caregivers.

4.3.3 Relationship with HIV positive child

Table 4.4 shows the relationship of the HIV positive child and the caregiver

Table 4.4 Relationship with HIV positive child

Relationship with child	Frequency	Percent
Biological mother	38	65.5
Biological father	6	10.3
Grand parent	7	12.1
Auntie	4	6.9
Other	3	5.2
Total	58	100.0

The researcher sought to establish the relationship between the HIV positive child and the respondents. Majority were biological mothers at 66%, 10% were biological fathers, 12% and7 % were grandparents and aunties respectively while 5% were others who included poster parents.

4.3.4 Number of HIV positive members

Table 4.5 shows the number of HIV positive members in the caregivers' household.

Table 4.5 Number of HIV positive members

HIV+ members	Frequency	Percent
One	8	13.8
Two	9	15.5
Three or more	14	24.1
Declined to answer	27	46.6
Total	58	100.0

The researcher sought to know the number of positive members in the household. The findings indicates that 46.6% of the respondents declined to answer, 24.1 % indicated over three, 15.5% indicated two while 13.8% indicated one member.

4.3.5 Source of income

Table 4.6 indicate that commerce and farming were the main source of income forming 53.5 %, unskilled/semi skilled engagements formed 22.4%, professionals formed 19%, while 5.2% are not engaged in an gainful activity.

Table 4.6 Main source of income

Source of income	Frequency	Percent
Farming	16	27.6
Business	15	25.9
Unskilled/semi skilled	13	22.4
Professional	11	19.0
None	3	5.2
Total	58	100.0

Although ART services at all government facilities were offered free of charge. Caregivers and health care providers felt that the cost of transport and health service user fees influenced paediatric ART non-utilization. This finding was supported by a study done on HIV patients in Senegal and Botswana that user fees, not only deter people from accessing AIDS care, but also create an obstacle to ARV treatment adherence (Castro, 2005). Focus group discussion found that those caregivers with unsteady income found it difficult to adhere to all paediatric ART clinic appointments hindering consistent utilization. This finding indicates that respondents who had steady income utilized much more than those with unsteady income.

4.3.6 Number of meals in a day

Table 4.7 indicates that majority of respondents 74% were able to afford three meals in a day. Those who could afford two and one meal in a day were 15.5 % and 10.3 % respectively. This means the underlying population was on average food secure.

Table 4.7 Number of meals in a day

Number of meals	Frequency	Percent
One	6	10.3
Two	9	15.5
Three	43	74.1
Total	58	100.0

FGD reported that when children take their treatment having not eaten any food they suffered from dizziness and therefore it was difficult to take ARV medicine without food. The more meals the care giver could afford in day the more likely that their children adhered to ART.

This finding suggests that lack of enough food influenced non utilization/non- adherence to paediatric ART.

4.3.7 Level of Education

Table 4.8 indicated that most respondents (37.9%) had attained secondary level of education and 29.3% had attained primary level of education. College education formed 20.7 %, adult education 8.6 % while no formal education constituted 3.4 %. This indicates that most of the residents in Embu district are literate.

Table 4.8 Level of Education

Level of education	Frequency	Percent
None	2	3.4
Primary education	17	29.3
Secondary education	22	37.9
College/university	12	20.7
Adult education	5	8.6
Total	58	100.0

The study found that high levels of education increased the care givers utilization of paediatric ART. The likely reason is that those patients could easily understand and follow paediatric ART. Three percent of respondents who had no formal education had difficulties utilizing and adhering to paediatric ART. These findings are supported by studies on HIV-patients in South Africa and USA among whom those who lacked education did not adhere to ARV treatment (Rodriguez et al., 2000).

4.3.8 Use of ARV drugs

Table 4.9 indicated that 79% of the respondents felt that ARVs are used to reduce progression of HIV, 16% think it's for reducing pain while 5% think it's for curing HIV.

Table 4.9 Use of ARV drugs

Use of ARVs	Frequency	Percent
Curing	3	5.2
Reducing pain	9	15.5
Reducing progression of HIV	46	79.3
Total	58	100.0

4.3.9 Source of ARV drugs

Table 4.10 indicates that majority of respondents 81% said that government health facilities are the source of ARV drugs. Three percent said that they would get ARV drugs from a chemist in case of ARV drugs stock out, 2 % said that they would get ARV from a friend, 14% said that they could get ARV drugs from mission hospitals.

Table 4.10 Source of ARV drugs

Source of ARVs	Frequency	Percent
Chemist/Pharmacy	2	3.4
Friends/relatives	1	1.7
Government health facilities	47	81.0
Mission hospitals	8	13.8
Total	58	100.0

Focus group discussion found that some guardians would share ARVs among children. This jeopardized adherence to paediatric ART.

4.3.10 Follow-up of ART regimen

Table 4.11 shows that majority of the respondents are able to follow their child's ARV therapy regimen forming 72% while 28% indicated to the contrary.

Table 4.11 Follow-up of ART regimen

Follow of ART regimen	Frequency	Percent
Yes	42	72.4
No	16	27.6
Total	58	100.0

4.3.11 Importance of completing treatment

Table 4.12 indicate that 81% of the respondents were informed of the importance of completing the full course of treatment while 19% indicated that they were not informed.

Table 4.12 Information on importance of completing treatment

Importance of adherence	Frequency	Percent
Yes	47	81.0
No	11	19.0
Total	58	100.0

4.3.12 Information on Drugs side effects

Table 4.13 indicates the caregivers' responses on ARVs side effects information

Table 4.13 Information on Drugs side effects

Drugs side effects	Frequency	Percent
Yes	50	86.2
No	8	13.8
Total	58	100.0

When asked whether they were informed by the health workers of the side effects and interactions of the drug(s) prescribed, 86.2% agreed while 13.8 % disagreed.

4.3.13 Drugs side effects

Table 4.14 indicates caregivers' responses on nursing ARVs side effects.

Table 4.14 Nursing drugs side effects

Nursing side effects	Frequency	Percent
Yes	7	12.1
No	45	77.6
Not sure	6	10.3
Total	58	100.0

The researcher enquired whether the child parents/guardians were taking care of any adverse effects to the medication at the time of the study. In table 4.14 below, 77.6% disagreed, 12.1% agreed while10.3 % were not sure IDIs reported that it was at times difficult for care givers to differentiate between HIV manifestation symptoms and drug adverse reaction.

4.3.14 Action taken after adverse effects

Table 4.15 indicates that 17% of the respondent stops the child prescribed anti retroviral drugs if the child has any adverse effects, 22% consults fellow caregivers on appropriate action to take while 60% will seek guidance from health care personnel.

Table 4.15 Action taken after adverse effects

Action after adverse effects	Frequency	Percent
Go to hospital for review	45	77.6
Stop the medication	10	17.2
Seek an opinion from a fellow caregiver	3	5.2
Total	58	100.0

Focus group discussion and IDIs reported ARVs side effects as a factor in defaulting ART. Caregivers would stop ARVs if the child had adverse reactions such as skin rashes, diarrhea, vomiting and especially during the first months of initiating ART. IDIs recommended support groups as key for caregivers since guided discussions and psychosocial support strengthens caregivers to diagnose and seek medical advice for adverse reactions.

4.3.15 Ever been tested of HIV

Table 4.16 indicates that majority of the respondents have been tested of HIV at 62%. 31 % had never had a HIV test while 7% declined to answer.

Table 4.16 Ever been tested of HIV

HIV test	Frequency	Percent
Yes	37	63.8
No	18	31.0
Declined to answer	3	5.2
Total	58	100.0

Focus group discussion reported that knowledge of the caregivers HIV status determines in a way the utilization of paediatric ART. Caregivers on ART are more likely to ensure that their children adhere to ART.

4.3.16 Importance of child knowing HIV status

Most respondents, 36% felt that it's not important for the child to know their HIV status, 26% declined to answer, 24% agreed while 14% were not sure.

Table 4.17 Importance of child knowing HIV status

Child knowing HIV status	Frequency	Percent
Yes	15	25.9
No	21	36.2
Not sure	8	13.8
Declined to answer	14	24.1
Total	58	100.0

Focus group discussion revealed that in households where the head was a mother and she was infected with HIV, disclosure to the children was difficult. For instance one woman reported failing to take ARV treatment in presence of her children because she feared that her children may abandon her if they find out that she the cause of their predicaments. A participant quipped that if the child know his status, he may disclose to others and hence the family will be treated with a lot of disgrace. This confirms Cohen et al.., 1995; Goldie et al.., 1994 that very high degree of stigma associated with HIV infection and the notion of shame makes it virtually impossible for parents to confide their diagnosis.

4.3.17 Opinion on ART

Table 4.18 presents the opinion of caregivers on ART.

Table 4.18 Opinion on ART

Opinion on ART	Frequency	Percent
Approve	53	91.4
disagree	2	3.4
undecided	3	5.2
Total	58	100.0

The researcher sought to find out the respondents opinion regarding ART therapy, 91% said they approved ART, 3% disagreed with the approval while 6% were undecided

4.3.18 Positive effect of ARV

Table 4.19 indicates the caregivers believe towards the positive effects of using ARVs.

Table 4.19 Positive effect of ARV

Positive effects of ARVs	Frequency	Percent
Yes	53	91.4
No	5	8.6
Total	58	100.0

When asked to whether they think that ARV will have a positive effect on their child's health, 91% agreed while 9% had no confidence of the positive effect.

4.3.19 Benefits of using ARVs

Table 4.20 indicates respondents benefits derived from using ARVs.

Table 4.20 Benefits of using ARVs

Benefits of ARVs	Frequency	Percent
Gained more weight	14	24.1
No more frequent sickness	22	37.9
Child grows normally	22	37.9
Total	58	100.0

No more frequent sickness and normal growth of the child was cited as the most benefit the children gained from using ARV drugs at 38% each, while 24% indicated to have gained more weight.

4.4 Societal Factors

Societal factors were analyzed and presented in frequency tables

4.4.1 Disclosure of child's HIV status

Table 4.21 indicates that majority of the respondents (93.1 %) had never disclosed the HIV status of their children to anyone while 6.9% had disclosed.

Table 4.21 Disclosure of child's HIV status

Disclosure of child HIV status	Frequency	Percent
Yes	4	6.9
No	54	93.1
Total	58	100.0

Respondents who had disclosed their child's HIV status had done so to family and support group members. The use of family members and peers to enhance ART adherence has emphasized the importance of social support in the treatment of HIV patients (Alice and Friendland, 1998). Key informants emphasized the need of caregivers to belong to a support group to enhance adherence and utilization of paediatric ART services.

4.4.2 Avoidance of friends and relatives

Table 4.22 presents the views of respondents on avoidance of friends or relatives.

Table 4.22 Avoidance of friends and relatives

Avoidance of friends/relatives	Frequency	Percent
Yes	11	19.0
No	47	81.0
Total	58	100.0

Majority of respondents 81 % said that they did not avoid friends or relatives and neither did friends or relatives avoid them due to the HIV positive child. However 19 % felt that they were not closely associating with relative or friends due to the HIV positive child under their care indicative of social/self stigma. Stigma was mentioned by FGDs as the cause of people avoiding caregivers or vice versa. Rao et al (2007) and Dlamini et al.

(2009) have linked AIDS stigma to lower adherence to ART. IDIs mentioned stigma as a main hindrance for people accessing ART services.

4.4.3 Reminder to give ARVs

Table 4.23 indicates that 44.8 % of the respondents had been supported to adhere to ART as opposed to 55.2 % who has had no support.

Table 4.23 Reminder to give ARVs

Reminder to give ARVs	Frequency	Percent
Yes	26	44.8
No	32	55.2
Total	58	100.0

The researcher sought to establish whether in the last one month, the respondents had any family or community member who supported (reminded or encouraged) them to give their children ARV medications. Key informants recommended caregivers enrollment into support groups as key in strengthening disclosure, psychosocial support hence enhancing utilization and adherence to paediatric ART.

4.4.4 Importance of support group

Table 4.24 indicates that 66% of the respondents were positive on the importance of belonging to a support group while 31 % felt it was of no use. 3% were not sure.

Table 4.24 Importance of support group

Importance of support group	Frequency	Percent
No	18	31.0
Yes	38	65.5
Not sure	2	3.5
Total	58	100

Though majority of the participants acknowledged the importance of a belonging to a support group, FGD revealed that caregivers avoided being associated with support groups. This was associated with fear of been discriminated or stigmatized against by

community members. IDIs revealed that defaulter rate was high in children who discovered on their own why they were taking ARVs.

4.4.5 Use of traditional/herbal medicine

Table 4.25 indicates the use of traditional /herbal medicine as an alternative to ARVs.

Table 4.25 Ever used traditional/herbal medicine

Use of herbal medicine	Frequency	Percent
Yes	9	15.5
No	49	84.5
Total	58	100.0

Majority of the Embu district residents have never given their children traditional or herbal medicine as an alternative to ARVs forming 84% while 16% had. Focus group discussion found that six caregivers at one point had preferred traditional medicine because of the belief that traditional medicine could cure HIV. These caregivers could alternate ARV drugs and traditional medicine or abandon ARV. Three caregivers said that they consulted spiritual healers, their children were prayed for, believed they got healed and abandoned ARV treatment. Later, they got very ill and resumed to paediatric ART. ARVs were cited to be more effective than Herbal medicine at 93%.

4.5 Health Care Delivery System

4.5.1 Avoidance of visiting pediatric ART sites

Table 4.26 indicates that 56.9 % of the respondents avoid being seen walking into the Comprehensive Care Clinic for pediatric ART services while 43.1% do not.

Table 4.26 Avoidance of visiting pediatric ART sites

Avoidance of ART sites	Frequency	Percent
Yes	33	56.9
No	25	43.1
Total	58	100.0

4.5.2 Integrating CCC to outpatient services

Table 4.27 indicates that 69 % of the respondents feel that CCC services should be integrated with other outpatient services while 31% disagreed.

Table 4.27 Integration of CCC to outpatient services

Integration of CCC	Frequency	Percent
Yes	40	69.0
No	18	31.0
Total	58	100.0

Key informants mentioned lack of proper functioning laboratory and insufficient counseling rooms, inadequate staffing, "opt out" testing for children, poor referral mechanisms between CCC and other areas of hospital where children present, lack of knowledge in public about available treatment for children, weakness in clinical diagnosis skills and inadequate capacity to handle paediatric HIV cases as factors influencing non-adherence to paediatric ART. Focus group discussion revealed that poor clinical setting and poor service delivery strongly influenced non-utilization to ART. Stand alone CCC were described as stigmatizing and integration of CCC to other services recommended.

4.5.3 Pediatric ART services waiting time

Table 4.28 indicates that majority of the respondents 67.2 % queued for less than one hour before receiving pediatric ART services, 29.3 % queued for between 2-3 hours while 3.4 % queued for more than 3 hours.

Table 4.28 Pediatric ART services waiting time

ART services waiting time	Frequency	Percent
Less than one hour	39	67.2
2-3 hours	17	29.3
More than 3 hours	2	3.4
Total	58	100.0

4.5.4 Medication refill challenges

The researcher sought to know if the respondents have any challenges in accessing the medication for refill, 69% said they don't while 31% agreed. All the respondents agreed that the health care workers encourage them and their children to consistently adhere to ART and that privacy is normally maintained during consultation.

Table 4.29 Medication refill challenges

ARV refill challenges	Frequency	Percent
Yes	18	31.0
No	40	69.0
Total	58	100.0

Key informants mentioned shortages of appropriate paediatric formulations, poor packaging (for example nevirapine was been packaged in syringes) while some ARV drugs were unpalatable as key challenges.

4.6 Level of utilization of paediatric ART

Table 4.30 indicates the level of utilization of paediatric ART in Embu district.

Table 4.30 Level of utilization of paeditric ART

Utilization of paeditric ART	Frequency	Percent
Cumulative number of children enrolled for ART	1036	100
Total number of children currently on ART	764	73.8
Total number of defaulters in the last 3 months	38	3.7
Number of children who have died or could not be traced	234	22.6

The mean defaulter rate was 3.7 % indicating that ART adherence rate was 74 %. This means that the level of ART adherence in the study area is sub-optimal (<95%). Antiretroviral therapy adherence rate in the study areas was relatively high 74% compared to findings of a study in developed countries on HIV patients among whom ART adherence was 55 % (Millis et al., 2006). The adherence rate (74%) found in this

study was less than that found by Sarna et al. (2005) at Mombasa Kenya, which was greater than 95%.

4.7 Correlation analysis of dependent and independent variables

Correlation is a term that refers to the strength of a relationship between two variables. A strong, or high, correlation means that two or more variables have a strong relationship with each other while a weak, or low, correlation means that the variables are hardly related. Correlation coefficients can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A 0.00 value means that there is no relationship between the variables being tested.

In order to determine the strength of the association, the researcher carried out correlation analysis using Statistical Program for Social Scientists (SPSS) program. The correlation table displays Pearson correlation coefficients, significance values and the number of cases with non missing values (N).The values of the correlation coefficient indicates the direction of the relationship, positive or negative.

The significance level or p-value is the probability of obtaining results as extreme as the one observed .If the significance level is very small, less than 0.05 then the correlation is significant and the two variables are linearly related. If the significance level is relatively large, then the correlation is not significant and the two variables are not linearly related. The following associations emerged from the analysis.

Table 4.31 Correlation between dependant and independent variables

		Proportion adhering to ART	No. of meals per day	ART Opinion	Avoids CCC	waiting time to receive ART services	Age of respondent	Relationship with child	Education level
Proportion adhering to ART	Pearson Correlation	1	.065	.418**	.023	-.159	.251	-.085	.125
	Sig. (2-tailed)		.626	.001	.864	.233	.058	.524	.351
	N	58	58	58	58	58	58	58	58
No. of meals per day	Pearson Correlation	.065	1	.160	-.208	.029	.288*	.042	.062
	Sig. (2-tailed)	.626		.230	.118	.831	.029	.756	.643
	N	58	58	58	58	58	58	58	58
ART opinion	Pearson Correlation	.418**	.160	1	-.033	-.193	.156	-.032	.032
	Sig. (2-tailed)	.001	.230		.805	.146	.243	.809	.813
	N	58	58	58	58	58	58	58	58
Avoids CCC	Pearson Correlation	.023	-.208	-.033	1	-.067	-.207	.174	-.191
	Sig. (2-tailed)	.864	.118	.805		.618	.119	.192	.151
	N	58	58	58	58	58	58	58	58

		Proportion adhering to ART	No. of meals per day	ART Opinion	Avoiding CCC	waiting time to receive ART services	Age of respondent	Relationship with child	Education level
Waiting time to receive ART services	Pearson Correlation	-.159	.029	-.193	-.067	1	.176	.236	.052
	Sig. (2-tailed)	.233	.831	.146	.618		.185	.074	.698
	N	58	58	58	58	58	58	58	58
Age of respondent	Pearson Correlation	.251	.288*	.156	-.207	.176	1	.400**	.136
	Sig. (2-tailed)	.058	.029	.243	.119	.185		.002	.308
	N	58	58	58	58	58	58	58	58
Relationship with child	Pearson Correlation	-.085	.042	-.032	.174	.236	.400**	1	.291*
	Sig. (2-tailed)	.524	.756	.809	.192	.074	.002		.026
	N	58	58	58	58	58	58	58	58
Education level	Pearson Correlation	.125	.062	.032	-.191	.052	.136	.291*	1
	Sig. (2-tailed)	.351	.643	.813	.151	.698	.308	.026	
	N	58	58	58	58	58	58	58	58

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

There is a significant positive correlation between the proportion of HIV positive children adhering to ART and the caregivers' attitude towards paediatric ART. The Pearson correlation is 0.418 significant level 0.001 < 0.01 implying that where caregivers' have a positive attitude towards paediatric ART the likelihood of utilizing and ensuring adherence to ART is high.

There is no significant correlation between the level of education and knowledge on the importance of adhering to paediatric ART. Pearson correlation is 0.125 significance level of 0.351 < 0.05. High/ low level of education does not translate to high/low utilization of paeditric ART.

There is no significant correlation between the proportion of HIV positive children adhering to ART and their relationship to the caregivers. The Pearson correlation is – 0.085 significance level 0.524 > 0.05. This means that the relationship of the child and caregiver is not significant I use and utilization of paediatric ART.

There is no significant correlation between the proportion of children adhering to ART and the waiting time to receive ART services in CCCs (Pearson correlation -0.159 significant level 0.233 > 0.05). This means there is no relationship between adherence and Art service waiting time in CCCs.

4.8 Qualitative Analysis

The themes and categories that resulted from the data analysis and interpretation process were grouped into two fields of experience, namely: responsibility and blame, and stigma and discrimination.

4.8.1 Responsibility and Blame

Participants in the present study expressed a tendency for one caregiver to assume a more dominant role in caring for the HIV positive child. This sense of responsibility was also associated with increased pressure and strain on the particular caregiver. For example:

A: My husband and I are HIV positive. Z (the HIV positive child) is our last born. We have four children. The three of us are on ART, but am the family doctor I'm the expert. I have to keep all our clinic appointments, even his (the husband).It was all resting on me; when Z turned ten and could not understand why he took drugs while his siblings didn't, I consulted his father to disclose his status to Z. But he was just there…Blank as ever. I had to make the decision… It's been a lonely road, because I've always been like the authority. And being the one with the most knowledge, being the expert, and always being the strong one… Nobody can know how the mother feels. You can think, but you can't actually feel that feeling. It's a 24-hour job, and the constant responsibility!

B: And then I also started thinking that maybe he (HIV positive child) would resent me later on… when he is a teenager he may decide that he hates me, because I put him through this. This is stressing me. I should have prevented this if only I enrolled in PMTCT program. What will I tell him if he confronts me? It's my entire fault.

Three research participants were of the opinion that their partners, who assumed less responsibility, often adopted a critical stance by blaming them for the difficulties that are associated with raising HIV positive children. These experiences are reflected in the following participant statements;

D: You can sometimes see that the father, sometimes he is blaming you. You are not strict, you are too soft, you are not disciplining the child enough, or I don't know.

T: My husband believes I brought the virus home.

P: You know men….. It's always us women to blame for everything

Leighton (1969) warns helping professionals to pay careful attention to the social and behavioral implications of guilt and the allocation of blame in their service rendering to caregivers of chronically ill children. Whereas male caregivers are more likely to place

attributions of blame in external sources, such as their spouses, female caregivers are more likely to place attributions of blame in themselves.

4.8.2 Experience surrounding stigma and discrimination

Participants expressed concerns of the society judging HIV positive persons harshly. These experiences are reflected in the following participant statements;

C: One day K (HIV positive child) came home crying….I thought he had fallen down or hit by something, I soothed him but he just sobbed. I enquired what had happened and in between sobs he said he had been chased away from his best friend (J) house by J's mother. She told him K he will infect J with HIV, and instructed J never to play with him again. These are the experiences one has to learn to live with….. It's dehumanizing when everyone isolates you and talks bad about your condition, call you names and more so as a child, denies you the joy of being a child.

E: It's sad, even teachers who are expected to be knowledgeable in HIV modes of transmission are discriminating our children. X (HIV positive child) is in class seven; He has to carry his plate, spoon and cup to school because anytime he eats with the school utensils, other students will not accept to use those utensils ever again. A teacher once instructed students to soak a plate he had used in Jik (antiseptic detergent) to kill the HIV…..Some children have been forced to drop out of school when it becomes unbearable. Something must be done to stop this.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATION

5.1 Introduction

This chapter provides a summary of findings, discussions, conclusions and recommendations on the factors influencing the utilization of paediatric antiretroviral services in Embu district.

5.2 Findings and Discussions

The main findings are summarized in terms of the stated objectives and sub-sections of the questionnaire.

5.2.1 Objective 1(Section A) Individual factors and utilization of paediatric ART

Majority of the respondents (caregivers) were women at 84.5 %. This confirms the findings of KDHS 2008/09 which indicates feminization of the epidemic with women bearing the greatest burden of HIV and AIDS. The main source of income was farming, business related ventures, and unskilled/ semiskilled labor. Income was crucial in the utilization of health services. Although ART services at all government facilities were offered free of charge. Caregivers and health care providers felt that the cost of transport and other health service user fees such as laboratory test charges influenced paediatric ART non-utilization. This finding was supported by a study done on HIV patients in Senegal and Botswana that user fees, not only deter people from accessing AIDS care, but also create an obstacle to ARV treatment adherence (Castro, 2005).74 % of households were food secure as characterized by ability to afford three meals in a day and this enhanced utilization of paediatric ART. Drug side effects were cited to be common with improper feeding thus non adherence. However, there was no significant correlation between education and adhering to paediatric ART regime. It was found that the majority of the respondents were knowledgeable about the use of ARVs and service accessibility. Caregivers who have had a HIV test or were on ART were more likely to ensure that children under their care adhered to ART. Majority of children on ART were not informed why they were on treatment and this jeopardized future utilization once they

discovered on their own.91 % of the respondents approve paediatric ART. It can be concluded from these findings that the respondents displayed a high level of paediatric ART services availability and use but that they lacked the economic power to access and utilize the services as well as supportive disclosure skills to disclose the HIV positive status to their children

5.2.2 Objective 2 (Section B) Societal factors and utilization of paediatric ART

Only 7 % of caregivers had disclosed the child's HIV status to family or support group members. The use of family members and peers to enhance ART adherence has emphasized the importance of social support in the treatment of HIV patients (Alice and Friendland, 1998). 19 % felt that they were not closely associating with relative or friends due to the HIV positive child under their care and were avoiding relatives/friends or felt that they were been avoided, a proxy indicator to stigma. The study found that stigma was prevalent in Embu district. Social support was low and majority of the caregivers did not belong to support group main reason cited being fear of being stigmatized or discriminated as a result. The study found that there is a negative correlation between the proportion of children on ART and disclosure of Child's HIV status (Pearson correlation -0.389 significant level $0.003<0.05$) Rao et al (2007) and Dlamini et al. (2009) have linked AIDS stigma to lower adherence to ART. 16% of caregivers had a tone point in time abandoned ART for traditional herbal medicine or spiritual healers. It can be concluded from these findings that stigma, lack of social support, non disclosure and traditional herbal medicine has jeopardized paediatric ART utilization.

5.2.3 Objective 3(Section B) Health care delivery system and utilization of paediatric ART

Stand alone CCC in government facilities was found to be influencing non utilization of ART services with 57% of caregivers expressing fear of being seen walking into the CCC and 69% suggesting that CCC should be integrated with other outpatient services. ARVs drugs stock outs was still prevalent with 31% of caregivers citing challenges in medicine refills. Other some potential barriers include shortages of appropriate paediatric formulations, poor packaging, unpalatable ARVs, lack of proper functioning laboratory

and insufficient counseling rooms, inadequate staffing, "opt out" testing for children, poor referral mechanisms between CCC and other areas of hospital where children present, lack of knowledge in public about available treatment for children, weakness in clinical diagnosis skills and inadequate capacity to handle paediatric HIV cases.

5.3 Conclusions

The study set out to establish the factors that influence utilization of antiretroviral therapy. The study demonstrates that the research questions and objectives had been met. The study findings indicated that the level of utilization (74%) in Embu district, Kenya is sub optimal (less than 95%). Efforts to enhance utilization/adherence to paediatric ART by both guardians and health care providers were met by challenges that limited their success. Guardians lacked economic power to consistently meet their basic needs including transport to hospitals and payment of HIV related laboratory tests. Lack of staff capacity and poor health system infrastructure made it difficult for health care providers to address the challenges of paediatric ART utilization.

To improve adherence to ART, health care providers recommended that: NGOs dealing with HIV and AIDS interventions should link up with government health facilities to ensure success of paeditric ART programmes; continuous capacity building of health personnel as well as continuously educating guardians and community to eradicate stigma and discrimination which is still a huge obstacle to success of HIV prevention and treatment programs. The government also need to develop strategies no ensure consistent supply of paediatric ARVs. Guardians recommended that: the government should provide food and transport for those genuinely in need and provide income-generating activities among households caring for HIV positive children.

5.4 Recommendations

To enhance ART adherence the study recommends to the Ministry of Medical Services, Ministry of Public Health and Sanitation and other stakeholders to:

i. Develop strategies to ensure food security in households with children living with HIV and AIDS.

ii. Intensify health education campaigns against stigma and promote family and community support for households with children living with HIV and AIDS.

iii. Ensure adequate and consistent paediatric ARV drug formulations in government health facilities.

iv. Formulate strategies to guide supportive disclosure of HIV status of children.

5.5 Suggestion for Further Research

Further research in order to enhance the paediatric ART Programme is recommended on the following topics:

i. An investigation into the development of effective intervention programmes to address fear of possible stigma and discrimination against caregivers.

ii. An investigation to establish the extent to which of supportive disclosure influences the utilization of paediatric ART.

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APPENDICES
APPENDIX I: LETTER OF TRANSMITTAL

UNIVERSITY OF NAIROBI,
P.O BOX 30197,
NAIROBI.
20TH, DECEMBER, 2011

TO THE RESPONDENTS
EMBU GOVERNMENT FACILITY CCCs

Dear Sir/Madam,

RE: COLLECTION OF DATA

I am a post graduate student at the University of Nairobi studying Masters of Art in Project Planning and Management. I am undertaking a study on the factors influencing the utilization of pediatric antiretroviral therapy (ART) services. The primary caregivers (parents/guardians) of children diagnosed or living with HIV have been found to play a very vital role in enhancing or inhibiting the utilization of pediatric ART services. This study seeks understand the areas in which these caregivers need support in terms of knowledge, cultural obstacles, supportive HIV disclosure to enhance of utilization of pediatric ART.

Your health facility has been chosen for the study. The choice is based on your strategic importance in the achievement of objectives of the study. The information obtained will be confidential and purely used for academic purposes and the findings of the research report shall be made available to you upon request.

I appreciate your willingness in helping me to undertake this research effectively.

Thanking you in anticipation.

Yours faithfully,

Catherine Mutuku

APPENDIX II: QUESTIONNAIRE

Structured interview guide for caregivers of children living with HIV.

Questionnaire No.....

Study site.....

A. Individual Factors

(Please use black ink to tick where appropriate)

1. Gender /sex of the respondent (a) Male [ ] (b) Female [ ]
2. Age of respondent in years_____
3. Relationship of the respondent with the HIV positive child
   - a) Biological mother [ ]
   - b) Biological father [ ]
   - c) Grandparent [ ]
   - d) Auntie [ ]
   - e) Other: .....
4. Number of HIV positive members in your household
   - a) One [ ]
   - b) Two [ ]
   - c) > three [ ]
   - d) Declined to answer [ ]
5. What is the main source of income for your household?
   - a) Farming [ ]
   - b) Commerce/business [ ]
   - c) Unskilled/ semi skilled labour [ ]
   - d) Professional [ ]
   - e) None [ ]

g) Other specify.....

6. How many meals do you afford to take on an average day in your household?

a) One [ ] b) Two [ ] c) Three [ ]

7. What is your level of education?

a) None [ ]
b) Primary education Std 1- 8 [ ]
c) Secondary education form I- IV [ ]
d) University/college education [ ]
e) Adult education [ ]

8. In your view, what are ARV drugs used for?

a) Curing [ ]
b) Reducing pain [ ]
c) Reducing progression of HIV [ ]
d) I don't know [ ]

9. Where can ARV drugs be obtained?

a) Chemist/ pharmacy [ ]
b) Friends/ relatives [ ]
c) Government Health central, hospitals and clinic [ ]
d) Mission hospitals/clinics [ ]
e) Other specify.....

10. Are you able to follow your child's ARV therapy regimen? a) No [ ] b) Yes []

11. Does the child under your care complete the full course of treatment?

a) Yes [ ] b) No [ ]

12. Were you told about the side effects and interactions of these drug(s) given?

a) Yes [ ] b) No [ ]

13. Does the child, you are taking care of, have any adverse effects to the medication?

a) Yes [ ] b) No [ ] c) Not sure [ ]

14. What action do you take when the child starts showing the adverse effects of the treatment?

a) Go to hospital for review [ ]

b) Stop the medication [ ]

c) Seek an option from a fellow caregiver [ ]

d) Other please specify: .....

Attitude towards HIV

15. Have you ever been tested for HIV? a) Yes [ ] b) No[ ]

16. Do you think that health workers there keep people's HIV test results confidential and do not reveal them to anyone outside the health clinic?

a) Yes [ ] b) No [ ] c) Declined to answer [ ]

17. Do you think it is important for the children to know their HIV status?

a) Yes [ ] b) No [ ] c) Not sure [ ] d) Declined to answer [ ]

18. What is your opinion regarding ART therapy

a) Approve [ ] (b) Disagree [ ] (c) Undecided [ ]

19. Do you think that ARV will have a positive effect on your child's health?

a) No, [ ] b) Yes, [ ]

20. What benefits have your child gained from using ARV drugs?

a) Gained more weight [ ] b) No more frequent sickness [ ]

c) Child grows normally now [ ]

B. Societal Factors

21. Have you ever disclosed the status of your child to anyone? a) No [ ] b) Yes [ ]

22. If yes, who did you disclose to?

a) Relative [ ] b) Friend [ ] c) church member [ ] d) School teacher [ ]

Other.....

23. Do you avoid friends or relatives because of your child's illness? a) No [b) Yes [ ]

24. In the last one month did you have any family or community member who supported? (reminded or encouraged) you to give your child ARV medications?

a) No [ ] b) Yes [ ]

25. If yes, who was the person who supported you? (Check one response only)

a) Immediate member of family (specify) [ ]

b) Nurse [ ]

c) Social Worker/Community Health Worker [ ]

d) Friend [ ]

e) Other specify.....

26. Do you think it is important to belong to a support group?

a) Yes [ ] b) No [ ] c) Not sure [ ]

27. Have you ever given your child traditional or herbal medicine as an alternative to ARVs?

a) Yes [ ] b) No [ ]

28. If yes, how do you compare ARVs to the herbal medicine in terms of effectiveness?

a) ARVs are more effective than Herbal medicine

b) Herbal medicines is more effective than ARVs

C. Health Care Delivery System

29. Do you avoid been seen walking into the Comprehensive Care Clinic for pediatric ART services a) Yes [ ] b) No [ ]

30. Should CCC services be integrated with other outpatient services? a) Yes [ ]b) No]

31. How long do you queue before receiving pediatric ART services?

a) Less than one hour

b) 2-3 hours

c) More than 3 hours

32. Do you have any challenges in accessing the medication for refill? a) Yes [ ] b) No [ ]

33. Do the health care workers encourage you and your child to consistently adhere to ART? a) Yes [ ] b) No [ ]

34. Is privacy maintained during consultation? No, [ ] Yes [ ]

Thank you for taking time to participate in this interview

APPENDIX III: KEY INFORMANT INTERVIEW GUIDE

Qualitative data collection tool for health care provider

1. Tell me the challenges you encounter with the primary caregivers on administration of ART to children.
    a) In-terms of attitude of the caregiver

_____

_____

_____

b) Compliance to drug usage / doses

_____

_____

_____

2. From your experience of interactions with the care givers, please let us know their position on how they handle the adverse effects of pediatric ARV

_____

_____

_____

3. What are the challenges in the availability of supplies of the pediatric ARV drugs
    a) Timeliness of the supplies

_____

_____

_____

b) Availability of the correct drug regime and combinations

_____

_____

_____

4. What do you think hinder care givers from utilizing to paediatric ART?

_____

_____

_____

5. What would you like improved in the CCC programme?

_____

_____

_____

_____

Thanks for your participation.

APPENDIX IV: FOCUS GROUP DISCUSSION GUIDE

I would like to inform you (participants) that your participation will be tape recorded. The information obtained will be treated in absolute confidentiality and will be used only for purpose of this study.

1. Pediatric ART are services received by HIV positive diagnosed children in health facilities. Are there any benefits children obtain from using paediatric anti-retroviral therapy?

   Yes_____ No_____ (note the frequencies)

If yes list the benefits below

_____

_____

_____

_____

If no, list the reasons

_____

_____

2. What factors hinder the utilization of paediatric ART?

_____

_____

_____

3. One needs a lot support when undergoing treatment, please let me know you views on belonging to a support group

_____

_____

_____

4. Do you belief it's important for the child under your care to know his/her HIV status?

   Yes_____ No_____ (note the frequencies)

   If no, why?

   _____

   _____

   _____

   _____

5. What would you like to be done to improve service delivery of paediatric ART?

   _____

   _____

   _____

6. What is your experience in caring for a HIV positive child?

   _____

   _____

   _____

   _____

Thanks for your participation.

APPENDIX V: UTILIZATION OF PEDIATRIC ART SERVICES

This is to be filled at each site (total of ten sites) from the clinic/site pediatric ART records

1. Cumulative number of children enrolled for ART at this site_____
2. Number of children currently on pediatric ART services at this site _____
3. Number of children who have defaulted in the last three months_____

Thank you for your cooperation.

MINISTRY OF PUBLIC HEALTH AND SANITATION

EMAIL ADDRESS ngalagarama @ yahoo.com
Mobile phone 0722718174

When replying please quote our reference

Ref: PASCO/ART/2/2012

PROVINCIAL AIDS& STI COORDINATOR
EASTERN SOUTH REGION
P.O. BOX 273
EMBU

DATE: 13TH FEBRUARY 2012

TO WHOM IT MAY CONCERN.

Dear Sir/Madam,

REF: AUTHORITY TO CARRY OUT RESEARCH

This is to authorize **Catherine Mutuku, ID. number 14715098** to interview guardians in Embu East, Embu North and Embu west districts Comprehensive Care Centres (CCCs); for her post graduate project paper on factors influencing the utilization of Paediatric ART.

Confidentiality, anonymity and privacy and informed consent will be strictly adhered to and this is purely an academic paper. Client participation in the study is voluntary.

Your assistance will be highly appreciated.

Thank you.

Sincerely,

PASCO EASTERN SOUTH
P. O. Box 273
EMBU

Dr. N. Garama
PASCO- EASTERN SOUTH
EASTERN PROVINCE