LINKAGE TO LONG TERM CARE OF NEWLY DIAGNOSED HIV EXPOSED AND HIV INFECTED CHILDREN AT KENYATTA NATIONAL HOSPITAL

A Thesis Submitted in Partial Fulfilment of Master in Medicine (Paediatrics) at the University of Nairobi

University of NAIROBI Library
0407060 3

By

Dr. Mutisya Immaculate, MBChB

June 2010

UNIVERSITY OF NAIROBI
MEDICAL LIBRARY

DECLARATION

I declare that this study is my original work and has not been published elsewhere or presented for a degree to any other university.

DR IMMACULATE MUTISYA
MBChB.

Signed _____ Date 13/10/10

This dissertation proposal has been submitted to the university of Nairobi with my approval as the University supervisor.

PROF. FRED WERE,
MBChB, MMed (Paediatrics), FNIC, PhD
Associate Professor Department of Paediatrics and Child Health, University of Nairobi.

Signed _____ Date NOV 2ND 2010

PROF. E. MALECHE OBIMBO
MBChB, MMed (Paediatrics), MPH (epidemiology)
Senior Lecturer Department of Paediatrics and Child Health, University of Nairobi.

Signed _____ Date Nov 1st 2010

DR NYAMBURA KARIUKI,
MBChB, MMed (Pediatrics), FHaem
Senior Lecturer Department of Paediatrics and Child Health, University of Nairobi.

Signed _____ Date 13-10-10

DEDICATION

I dedicate this work to my parents Mr & Mrs Daniel Katei Mutisya, you have been and you still are the most inspiring teachers in my life.

ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to

1. My supervisors Professor Fred Were, Professor Elizabeth Obimbo and Dr Nyambura Kariuki for their guidance, patience and support during this study.
2. The members of the Department of Pediatrics for their contributions into this study.
3. The statistician Mr. Philip for his assistance in data management and analysis.
4. All the caretakers and their children who participated in this study.
5. All members of KNH CCC, Mbagathi district hospital and Nyumbani children's home.
6. To my husband J. Mukeku and my daughter Amie, for their kind consideration and support during my study.

Table of Contents

LIST OF TABLES

LIST OF FIGURES

List of Abbreviations and Acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CDC	Centre for Disease Control
DNA	Deoxyribonucleic Acid
EID	Early infant diagnosis
HAART	Highly active antiretroviral therapy
HIV	human immunodeficiency virus
KNH	Kenyatta National Hospital
MCH	Maternal and child health
NASCOP	National AIDS and STD Control Program
OI	Opportunistic infection
PCR	Polymerase chain reaction
PEU	Pediatrics emergency unit
PMTCT	Prevention of mother-to-child transmission
PITC	Provider initiated testing and counseling
TB	Tuberculosis
VCT	Voluntary counseling and testing
WHO	World Health Organization

ABSTRACT

Background

Despite efforts to scale up provider initiated testing and counselling (PITC) and early infant diagnosis (EID) services, it is not known what proportion of newly diagnosed HIV infected and exposed children are successfully linked into long term care. The purpose of the study was to determine the proportion of newly diagnosed HIV exposed and infected children in KNH who are successfully linked to long term care and to identify and describe the common barriers to HIV care after diagnosis.

Methods

This was a short longitudinal survey. We enrolled and followed up newly diagnosed HIV exposed children and infected children referred for long term care from KNH. We verified linkage one week after the expected date of appointment as follows: by medical record for children referred to KNH CCC, Mbagathi district Hospital CCC and Lea Toto clinics and by telephone for those referred to other sites. Structured phone based questionnaires were used to evaluate barriers to care.

Results

We enrolled 195 children, 104 (53%) females and 91 (47%) males. Median age was 12 months (Interquartile range [IQR] of 5 to 21 months). One hundred and forty two children (73%) were confirmed HIV infected and 53(27%) were of indeterminate status. Ninety eight children (50%) were successfully linked into long term HIV care while 87(45%) were not linked. Ten children (5%) were lost to follow up. The most common barrier to care was nondisclosure of the child's HIV status to spouse (32%); this was closely followed by lack of information on long term HIV care (12%), lack of money for transport (11%) and family disruptions following revelation of the child's HIV status (11%). Other barriers included caregiver indecision to start care (8%), unavailability due to ill health (5%) or commitment at work (2%), stigma (6%), maternal death (5%) and seeking care from faith based healers (5%) or traditional healers (2%). A few caregivers (3%) were unable to explain reasons for defaulting.

Conclusion

Only half of newly diagnosed HIV exposed and HIV infected children are successfully linked to long term care. The main barriers to care emanate from the family unit, stigma and inadequate counselling and support of caregivers of these children.

1.0 Background and Literature Review

Introduction

Human Immune Deficiency Virus (HIV) is a single stranded RNA virus 9.2 kb in size from the family of *Retroviridae*, belonging to the *lentivirus* genus. HIV infection in children above 18 months is confirmed by a positive HIV antibody test. An HIV exposed child refers to a child born to a HIV infected mother, the child may be infected, uninfected or undetermined status. HIV DNA PCR test is done to determine the HIV infection status in children aged below 18 months; a positive result confirms infection while a negative test result rules out infection if the child has not breastfed for the last 6 weeks. Undetermined status refers to a negative HIV DNA PCR test in a breastfeeding child or a child who has ceased breastfeeding in less than 6 weeks, a confirmatory test is required 6 weeks after cessation of breastfeeding.

Epidemiology

There are approximately 2.1 million children living with HIV, of these, 90 per cent live in Sub-Saharan Africa [1]. More than 90% of HIV infections in children are acquired through Mother To Child Transmission (MTCT). In 2007, about 370,000 new infections in children were reported, giving an average of 1,200 new infections every day [1,2,3]. HIV/AIDS currently accounts for a 19% rise in infant mortality rates and a 36% rise in the under five mortality[4]. In Kenya, the mortality rate of HIV infected children is approximately 47/1000 [7]. Predictors of mortality in HIV infected children include, maternal illness, low CD4 counts and a high viral load [7].

Although the current coverage of Provider Initiated Testing and Counselling (PITC) in Kenya has not been documented, a study on uptake of PITC in KNH in 2006 demonstrated that more than 80% of caregivers of children admitted in the paediatric wards were willing to have their child tested for HIV [8]. Access to antiretroviral therapy in children continues to lag behind in spite of the scaling up of paediatric HIV diagnosis through Provider Initiated Testing and counselling (PITC) and Early Infant Diagnosis (EID) [9]. Similarly, Kenya continues to record high infant and childhood HIV related deaths. It is not clear whether the children who are diagnosed with HIV infection are thereafter successfully linked to long term HIV care. A survey done in Kenya in 2006, identified some gaps in the paediatric HIV service delivery package and especially in the linkage of HIV exposed and HIV infected infants from PMTCT to HIV care centres [10].

Natural History and Progression

Children vertically infected with HIV have a rapid disease progression. This is because of their immature immune function. HIV particularly infects CD4 positive cells. As a result, there is gradual decline of CD4 cells with subsequent proliferation of the virus. The viral load in children unlike adults remains relatively high in the first 24 months. An African study demonstrated high levels of HIV- RNA in the infected at birth in the first one year with subsequent mild decline in the levels in the second year of life [11] *[see Figure 1 below]*.

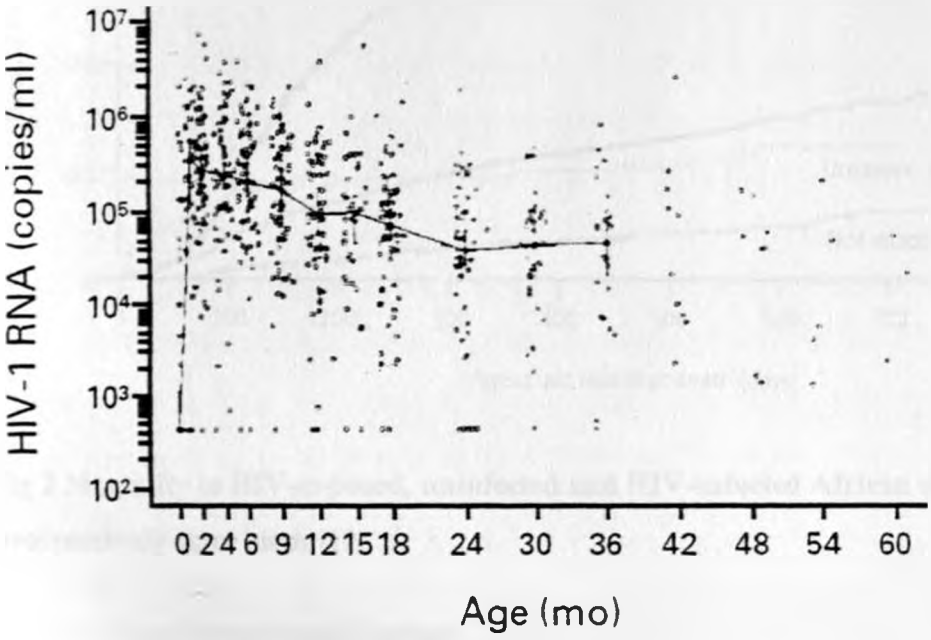

Fig1 Plasma HIV-1 RNA in Multiple Samples from 106 Infants with HIV-1[11]

Due to the rapid deterioration of immune function in children infected with HIV very high mortality rates are noted. This was demonstrated in a study done in Rwanda in 2004 [12] *[see figure 2 below]*.

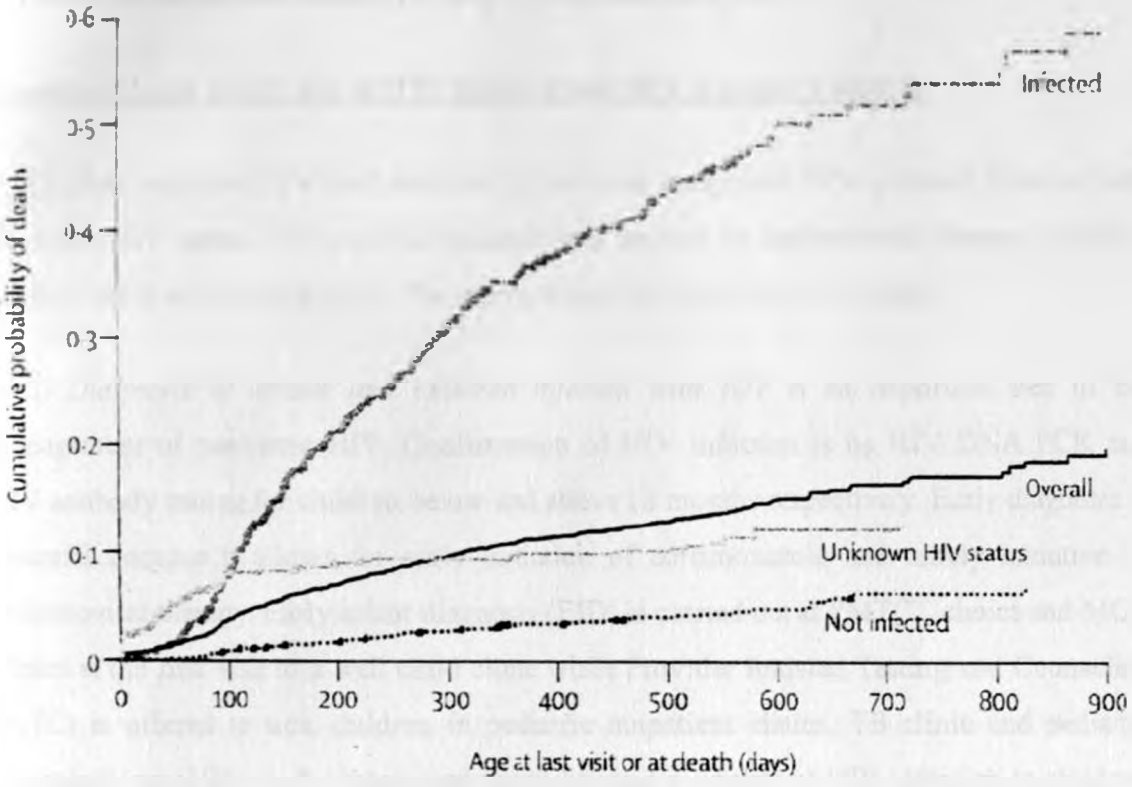

Fig 2 Mortality in HIV-exposed, uninfected and HIV-infected African children followed prospectively since birth [12].

Clinical Manifestation and Staging

The clinical manifestations of HIV infection vary widely among children. HIV infected babies appear normal at birth. Signs and symptoms develop over the first few weeks with most children showing evidence of infection within the first 12 months. HIV infected children often present with infections that are common among HIV negative children, however, there are certain clinical features that are associated with HIV infection which include; persistent generalized lymphadenopathy, pulmonary tuberculosis, hepatosplenomegally, oral candidiasis outside the neonatal period, recurrent pneumonia and chronic or recurrent diarrhea. In advanced immunosuppression, children begin to develop AIDS-defining illnesses which include; Pneumocystis *Jiroveci* pneumonia (PCP), HIV associated malignancies, HIV encephalopathy, lymphoid interstitial pneumonia (LIP), cryptococcal meningitis , disseminated CMV and Kaposi's sarcoma. The clinical progression of pediatric HIV infection has been summarized in four clinical stages by the World Health

Organization (*see appendix 1*). WHO has also developed pediatric HIV immunological staging based on the CD4 percentage (*see appendix 2*). While clinical staging is an indicator of the effects of immunosuppression to the body, the immunological staging shows the extent of destruction of immune cells (CD4 and T-lymphocytes) by HIV.

Benefits of Long term Care of HIV Infected and HIV Exposed Children

Children requiring HIV care services fall in three categories: HIV exposed children with unknown HIV status, HIV positive children who are not on antiretroviral therapy and HIV positive children receiving ART. The standard care of these children include:

i) Diagnosis of infants and children infected with HIV is an important step in the management of paediatric HIV. Confirmation of HIV infection is by HIV DNA PCR and HIV antibody testing for children below and above 18 months respectively. Early diagnosis is essential because it allows for early initiation of cortimoxazole and timely initiation of antiretroviral therapy. Early infant diagnosis (EID) is carried out at PMTCT clinics and MCH clinics at the first visit to a well child clinic while Provider Initiated Testing and Counseling (PITC) is offered to sick children in pediatric outpatient clinics, TB clinic and pediatric emergency unit. Due to the associated morbidity and mortality of HIV infection in children, newly diagnosed HIV infected or HIV exposed children with unknown status should be linked to centers of HIV care as soon as possible [13].

ii) Counseling the care giver; care givers of HIV infected and HIV exposed children require counseling on the following issues: the importance of cotrimoxazole prophylaxis, HIV testing for siblings, referral to an HIV care centre and consistent follow up schedule. Counseling is geared towards helping care givers enroll in long term care, deal with the psychological effects of a positive test result, help them make decisions on disclosure issues and encourage them to remain on long term care [14].

iii) Cotrimoxazole prophylaxis: it has been shown that cotrimoxazole has beneficial effects towards prevention of invasive bacterial infections such as pneumocystis jirovecii pneumonia, non-typhoid salmonella, toxoplasmosis and *Strep. Pneumoniae* as well as malaria and diarrheal diseases. It is indicated for all children with confirmed HIV infection and the HIV exposed children whose HIV infection status is unknown [13].

iv) Regular growth and development monitoring: this is essential because growth faltering may be the first sign of HIV infection in a child. If unchecked, growth faltering

often leads to severe malnutrion and or failure to thrive which increases the morbidity and mortality. Management of growth failure requires aggressive assessment and investigations to rule out any underlying opportunistic infection and adequate nutritional support. Evaluation of developmental milestones is also important because delayed milestones may be a sign of HIV encephalopathy [13].

v) Immunisation: HIV-infected and HIV-exposed children should be immunized according to the routine national immunizations schedule. Live vaccines such as BCG and yellow fever are contraindicated if the child has clinical AIDS. Routine vitamin A supplementation and deworming should also be administered [13].

vi) Aggressive treatment of opportunistic infections: life threatening opportunistic infections (OI's) are the major cause of morbidity and mortality associated with HIV infection in children. High index of suspicion. investigations and aggressive treatment of OI's is essential. Acute opportunistic infections must be dealt with before initiation of ARV's [13].

vii) Antiretroviral therapy: once the diagnosis of HIV infection is confirmed in a child. clinical and immunological staging is carried out to assess the child's eligibility for therapy. The child should be started on treatment if they meet the medical criteria for initiation of ART. WHO recommendations for starting antiretroviral therapy in children are shown below (*Table1*).

Table 1: WHO criteria for initiating Antiretroviral Therapy in HIV Infected Children (Revised in 2008) [15].

Criteria for starting ART in children				
	<12Months	12-35Months	36-59 Months	>5yrs
CD4 %	ALL	<20%	< 20%	<15%
Absolute CD4	ALL	<750	< 350	<200

In Kenya, the criteria for ART eligibility in children is as per the National AIDS and STI Control Programme (NASCOP) . These guidelines are as shown below (Table 2)

Table 2: NASCOP criteria for initiating Antiretroviral Therapy in HIV Infected Children 2008 [16].

Age	<18Months	18months- 5years	6-12 Years
CD4 percentage	ALL	<25%	<20%
CD4 Count	ALL	<1000	<350
WHO clinical stage	ALL	3 &4	3& 4

Long term care & follow up of HIV exposed and HIV infected children occurs in Comprehensive care centers (CCC). These centers can be found in primary health care facilities, secondary or tertiary hospitals, faith based organizations, non –governmental organizations, orphans and vulnerable children institutions. Comprehensive Care Centers in the hospitals are either integrated within existing hospital departments such as PMTCT or paediatric outpatient clinics or are set up as standalone CCC's which receive referrals of newly diagnosed HIV infected patients from the points of diagnosis. This later model is common in many hospital set ups.

The main activities of the CCC is enrolment and long term care and follow up of HIV infected children. The ongoing care for children on ART includes; monitoring treatment adherence, providing the necessary ARVs on a monthly basis, referral for laboratory investigations and re-assessment as required, assessment for drug side effects or other, complications, routine care for immunisation and weight monitoring, management of intercurrent infections, provision of co-trimoxazole prophylaxis for PCP, counselling and support of the parents/caregivers and arranging for palliative care where appropriate with the support of family and community based organizations [14].

HIV exposed children require a structured follow up system to ensure that their risk of infection remains low and that if they get infected they are enrolled into long term care immediately. On the other hand, HIV infected children require early initiation into HIV care and long term follow-up for timely initiation of antiretroviral therapy, prevention and treatment of opportunistic infections. These measures have been shown to reduce morbidity and mortality amongst HIV infected children [15].

KNH is a tertiary referral hospital which receives referrals from all over the country. Provider Initiated Testing and Counselling (PITC) is provided at various entry points which include: the pediatric Emergency Unit, the pediatric wards, newborn unit, MCH clinic, PMTCT clinic, pediatric outpatient clinic and TB clinic. Confirmation of HIV infection is through HIV antibody rapid tests and HIV DNA PCR test for children above and below 18 months respectively. Children with undetermined HIV status are followed up closely; their mothers are counseled on infant feeding options and allowed to make informed decisions on the type of feeding they would like to adopt. HIV testing is done 6 weeks after cessation of breastfeeding.

Linkage to Care of HIV Exposed And HIV Infected Children

Linkage is defined as having an initial visit to a HIV care centre after diagnosis with subsequent enrolment on long term care and follow up. It means creating a connection between the points of diagnosis with centres of HIV care. This connection is crucial, because diagnosing HIV infection, while important, is clearly not sufficient. Once the diagnosis of HIV infection is made, it is imperative that the patient be linked to care and prevention services. The children require timely initiation of cotrimoxazole prophylaxis and Antiretroviral Therapy (ART).

In KNH, majority of the HIV infected children are referred to KNH CCC. For patients identified from the wards, the relevant information is filled in their discharge summary including a two week appointment to attend the CCC. For the children identified in other entry points, their guardians/parents are advised to visit the CCC as soon as possible. A small number of patients diagnosed at KNH are referred to other centers for HIV care. Such centres include: faith based organizations and city council clinics within or outside the city. The reasons for referral to these facilities include proximity to their areas of residence or that their parents being on follow up in those centres.

Currently, the CDC estimates that approximately a quarter of individuals who are infected with HIV are not engaged into long term HIV care and, as a result, only 56% of patients eligible for antiretroviral therapy in the USA are on treatment [17]. There is currently no data indicating the situation in developing countries.

Patients who have been successfully linked to and are receiving continued care have, in general, good clinical outcomes. HIV infected and HIV exposed children require structured follow up in order to reduce the morbidity and mortality associated with preventable and treatable opportunistic infections. Lack of linkage to care in children may therefore, lead to rapid deterioration of the child's health and subsequent death . HIV infected and exposed

children are more likely to die than other children in general population [18]. In a cohort of HIV infected untreated Kenyan infants, 50% died before the age of 2 years [7]. Another study in Rwanda and Burundi demonstrated that children with HIV infection have 45% risk of death within the first 2 years and 62 % risk of death within the first 5 years [19]. Early enrolment in HIV care gives the child a chance to benefit from cotrimoxazole which has been shown to reduce hospital admissions, hospital stay and mortality by up to 43% [20]. Secondly, it provides an opportunity for timely initiation of antiretroviral therapy. A study in Kenya demonstrated gains of antiretroviral therapy in children comparable to results from the West: a reduction in hospital admissions from 62 % to 18 % and increase in CD4 percentage from 6.3% to 13.2% [21]. The South African CHER study demonstrated that early initiation of antiretroviral therapy in infants at 12 weeks can reduce infant mortality by up to 76 % [22]. There are better clinical outcomes with timely initiation of ART. American children started on HAART with advanced immunosuppression demonstrated failure to regain normal immune function even after 5 years of treatment [23]. A sub-Saharan African study demonstrated that children started on HAART in advanced disease were at a higher risk of death compared to those started early [24].

Barriers to HIV Care

There are multiple barriers in accessing HIV/AIDS medical care. Patients may forgo testing because of fear of stigmatization or fail to enter outpatient care after diagnosis. Some of reasons for failure to engage into long term careinclude: lack of knowledge on the importance of HIV care, stigma , lack of qualified personnel at the primary health facilities to educate, counsel and refer patients, presence of co morbidities such as mental illness ,substance abuse and presence ofmore pressing basic subsistence needs such as food, clothing, housing, childcare and transportation that compete with medical care priorities [25]. HIV-positive patients in in USA were interviewed using a questionnaire to measure geography/distance, medical and psychosocial resources, community stigma and personal resource as barriers to HIV care. In descending order, participants identified the following factors as barriers to HIV care: the level of knowledge about HIV among citizens in the community; community residents' stigma against people with HIV; lack of employment opportunities and supportive and understanding work environments; and personal financial resources [26].

To enhance linkage to care, interventions must be put in place to overcome the barriers that hinder enrolment to care. Recently published results of the Special Projects of National

Significance (SPNS) make it clear that outreach is the next important step to take as an intervention to enhance linkage to care of HIV infected persons [27]. A multicentered study by the Antiretroviral Research Study (ARTAS) proved that case management intervention increased access and usage of HIV care services. The study was a randomized control trial with two arms. On one arm newly diagnosed HIV patients were " passively" referred for long term care, while on the other arm, each patient was assigned to a case manager who had at least five contacts with the patient within six months of diagnosis. The interventions were designed to increase knowledge, motivation and skills as a way of reducing barriers and facilitating use of primary medical care. Those patients followed up by a case manager were found to be 40 percent more likely to seek care than those 'passively referred' [28].
Management of paediatric HIV is complex; affected families are faced with a myriad of medical and social problems that require multidisciplinary case management, integrating medical, social, mental health and educational services. Well structured systems need to be put in place to integrate preventive measures, long term care and treatment of HIV exposed and infected children together to ensure timely diagnosis and enrolment to care.

1.3 STUDY JUSTIFICATION

The course of HIV and AIDS is particularly aggressive in children. Without HIV treatment and care. HIV multiplies and destroys the child's defence to infection. leaving the child less able to resist pneumonia and other common childhood infections. About 50 % of children who acquire HIV from their mothers die before the age of two years from opportunistic infections such as diarrhoea and severe pneumonia [7. 25].

New evidence demonstrates that. early HIV diagnosis and antiretroviral therapy particularly for infants within the first 12 weeks significantly reduces infant mortality [26]. Currently WHO recommends initiation of ART for all infants under the age of 12 months as soon as possible. It is important to ensure that children with HIV infection are linked into HIV care soon after diagnosis in order to optimize infant and child survival.

Despite scale up of EID and PITC for children. the numbers accessing antiretroviral therapy still remains low; only 11 % of children who are eligible for HAART in Kenya are receiving it [29]. It is not clear whether the children who are diagnosed with HIV infection are successfully linked into HIV care facilities.

Approximately 45% of newly diagnosed HIV infected children in KNH pediatric wards are eligible for ART at the time of diagnosis [8]. It is unknown what proportion of these children are successfully linked to long term HIV care clinics for continued comprehensive HIV care after leaving the hospital.

There is anecdotal evidence that a significant number of newly diagnosed HIV infected children are not successfully linked to long term care. or are enrolled when they have advanced immunossuppression with observed high morbidity and mortality.

Approximately 30.000 children in Kenya are dying of HIV related illnesses annually [16]. This trend illustrates alarming outcomes of HIV infection amongst children. It is with this background that we decided to determine to what extend children who are diagnosed with HIV infection in our facility actually end up in long term care and to identify the barriers to HIV care in order develop future interventions for these children.

1.4 Objectives

1. To determine the proportion of newly diagnosed HIV infected and HIV exposed children at Kenyatta National Hospital successfully linked to long term HIV care.
2. To identify and describe the common barriers to linkage in to long term HIV care for newly diagnosed HIV exposed and HIV infected children .

2.0 Methodology

2.1 Study Design.

This was a short longitudinal survey.

2.21 Study Site

The study was conducted at the Kenyatta National Hospital (KNH) which is located in Nairobi, the capital city of Kenya. KNH is a tertiary referral hospital which provides primary and secondary care to children from Nairobi and its environs. Provider Initiated Testing and Counselling (PITC) is offered at various entry points including; the paediatrics wards, the paediatric emergency unit(PEU), PMTCT clinic, TB clinic, paediatric outpatient clinic and newborn units. Majority of the HIV exposed children are referred to the KNH CCC. Some children are referred to other HIV care centres in Nairobi on the basis of proximity to their areas of residence or if the caregiver/parent is enrolled on care in the same institution or HIV clinic.

2.22 Follow-up centres

HIV exposed and HIV infected children identified in KNH were referred to various centres of HIV care. These facilities included Lea Toto clinics in Nairobi, Mbagathi district hospital and City council clinics. The children who were not resident in Nairobi were referred to the nearest provincial or district hospital CCC.

2.3 Study Population.

Newly diagnosed HIV infected and exposed children aged between 0 and 12 years seen in the pediatric emergency unit , the paediatrics wards, PMTCT clinic, TB clinic and newborn unit.

Inclusion criteria.

1. All children aged 0 -12 years who were newly diagnosed with HIV infection or in determinate HIV status in KNH at the various entry points.

2. Consent given by caregiver.

3. Caregivers who had a telephone contact.

Exclusion criteria

1. Children enrolled in other HIV research projects at KNH.
2. Caregivers who did not have a telephone contact.

Case Definitions.

HIV status

1. HIV infection - a positive HIV antibody test for children above 18 months and a positive HIV DNA PCR for children below 18 months.
2. HIV exposure – a negative HIV DNA PCR for children below 18 months who are currently breastfeeding or have ceased breastfeeding in less than 6 weeks.

Linkage to care

1. Successfully linked to care – children who are brought to the HIV care centre one week after the expected date of appointment.
2. Not linked to care – children who are not brought to the HIV care centre one week after the expected date of appointment.

2.4 Sample size calculation

Sample size will be calculated using Fischer's formula

$$n = \frac{Z^2_{a/2} \times P(1-P)}{d^2}$$

where

n = sample size

$Z^2_{a/2}$ = the corresponding value to the 95% confidence level (1.96)

d = degree of precision (5%)

p = estimated proportion of patients enrolled in to long term care

CDC estimates that only 85% of patients with known HIV infection are enrolled into HIV care [16].

Therefore $n = \frac{1.96^2 (0.85)(0.15)}{0.0025}$

$n = 195$

A maximum sample size of 195 patients was targeted for the study.

If a degree of precision (d) of 10% is used:

$$n = \frac{1.96^2 (0.85)(0.15)}{0.01}$$

$n = 49$

Therefore, a minimum of 49 patients and a maximum of 195 patients will be targeted during the study.

2.5 STUDY PROCEDURES

2.51 Recruitment Procedure

Children were recruited from paediatric wards, the paediatric emergency unit (PEU), PMTCT clinic, TB clinic, MCH clinic, paediatric outpatient clinic and newborn unit. All newly diagnosed HIV infected and HIV exposed children were selected. For those who met the inclusion criteria, the caregivers were given a consent form as appropriate and included in the study. Patient and caregiver information was filled in the questionnaires, this information included: the sociodemographic data of the patient and caregiver, diagnosis/es, management plan (investigations and treatment prescribed), referral centre, expected date of appointment and at least one telephone.

2.52 Follow-up

Follow-up of patients was done 1 week after the expected date of appointment to establish if the children referred to the various centres of HIV were enrolled to care. We verified whether the child had successfully arrived at the centre of HIV clinic as follows; for 3 three commonest referral centers in Nairobi: KNH Comprehensive Care Clinic (CCC), Lea Toto clinics and Mbagathi district hospital CCC, the principle investigator visited the centers and checked their HIV care enrolment records, for children referred to other centres in or outside

Nairobi. the principle investigator contacted the children's caregivers via telephone to find out if they had enrolled their children into HIV care. Structured phone based interviews (*appendix iv*) were conducted for caregivers whose children failed to attend the clinic after hospital discharge. They were counselled on the importance of enrolling into care. The names of the children not enrolled to care after referral to KNH CCC. Mbagathi district Hospital CCC and Lea Toto clinics and the telephone contacts and physical address of their care givers were given to the social work teams at the respective centers for further counselling and follow up.

3.0 ETHICAL CONSIDERATIONS

(i) The study was conducted after written approval by the Department of Paediatrics and Child Health. University of Nairobi. the Kenyatta National Hospital Scientific and Ethical Review Committee. Mbagathi district hospital and Lea Toto clinics' health management teams.

(ii) The study was carried out on children whose parents/guardians have given informed consent.

(iii) Information gathered was treated with confidentiality and great caution will be upheld to ensure that there is no adverse exposure of the HIV status of the study patients.

(iv) Withdrawal from the study did not compromise the management and quality of care given to the patient. and this will be stated to the parents/guardians.

(v) There was no added cost to the patient.

(vi) Caregivers of patients not successfully linked to care were counselled and linked to social work teams of KNH. Mbagathi district hospital CCC and Lea toto clinics for follow up.

4.0 DATA ANALYSIS

Data entry and verification was done in Microsoft Access® databases. All data analyses were conducted using STATA statistical analysis package (Version 10.0, StataCorp, TX). Descriptive analysis of the basic socio-demographic characteristics of study participants was conducted for all the quantitative variables. The success in linkage to in linkage to care was described and represented in frequency tables and a bar graph. Data exploring the barriers to linkage were collected using open ended questions and initially analysed using qualitative methods. These responses were coded into themes emerging from the data. The coded responses were then used in a descriptive analysis of the barriers for linkage to long term HIV care.

A multivariable analysis of significant socio-demographic characteristics was conducted using logistic regression methods. All the variables that were significantly related to linkage to long term care in the chi square tests were included in the regression along with age, gender, HIV exposure and the referral site. Subsequently, independent variables that significantly influenced the success of linkage to long term care were reported.

5.0 RESULTS

Characteristics of Children Enrolled in to the Study

We enrolled one hundred and ninety-five children into the study. 53% of whom were females and 47% were males. The median age was 12 months (Interquartile range [IQR] of 5 to 21 months). Fifty- three children were HIV exposed and the remaining 142 children were infected. Thirty-five (66.0%) of the HIV exposed children were aged less than 6 months. Pneumonia and gastroenteritis were the most common admission diagnoses (52% and 18% respectively). Other common admission diagnoses were neonatal sepsis, malnutrition, meningitis, and TB (see table 3 below).

Table 3: Baseline Characteristics of the Study Population.

Characteristic	Number of children (n=195)	Percentage (%)
Age		
<18months	93	48
18mo – 5 yrs	82	42
6 – 12 yrs	20	10
Sex		
Male	91	47
Female	104	53
HIV Status		
Infected	142	73
Exposed	53	27
Admission diagnosis*		
Pneumonia	106	52
Gastroenteritis	35	18
Sepsis	18	9
Malnutrition	15	8
Meningitis	14	7
Tuberculosis	14	7

*the sum of admission diagnosis could add up to > 195 because of co morbid illnesses present in some children.

Caregiver Characteristics

All the children in the study were accompanied by a caregiver at the time of recruitment into the study. Median age of the caregivers was 28 years (Interquartile range [IQR] 24 to 31). Most (94.9%) caretakers were parents of the participating child, and only 2 out of all the parents described in this analysis were fathers (Table 2). Slightly more than one-half (60%) of caregivers were unemployed and were engaged in household duties. In about a quarter of the caregivers at least one of the parents was enrolled in an HIV care program either on cortrimoxazole prophylaxis or ARV's. Majority. 104 (56.5%) of the care givers did not know the HIV status of their spouses. These findings are summarized in table 4 below.

Table 4: Background Characteristics of Caregivers of Children Participating in the Study

Characteristic	Number of caretakers (n=195)	Percentage (%)
Age		
<20 yrs	6	3
20-29 yrs	118	61
>30yrs	71	36
Sex		
Male	2	1
Female	193	99
Relationship to the child		
Mother	183	94
Father	2	1
Other relative	10	5
Marital status		
Married	138	74
Single	43	23
Widow	6	3
Level of education		
No formal education	7	4
Primary	115	61
Secondary	58	30
Tertiary	10	5
Occupation		
Employed	67	39
Unemployed	103	61
Parent on HIV care		
Yes	47	25
No	138	75
Maternal ANC HIV test		
Positive	115	63
Negative	28	15
Unknown	41	22
Spouse's HIV status		
Positive	49	27
Negative	31	17
Unknown	104	56

Linkage to Long Term Care

All the children in the study were referred for follow up HIV care. Out of the 195 HIV children, 98 (50.3%) were linked to long term HIV care and 87(44.6%) did not attend clinic for follow up HIV care. Of these 87 children, 65 (33%) were not linked to care due to barriers while 15 (8%) and 7 (4%) were due to death or hospital admission respectively. Ten children (5.1%) were lost to follow up. The flowchart and pie chart below summarizes these results.

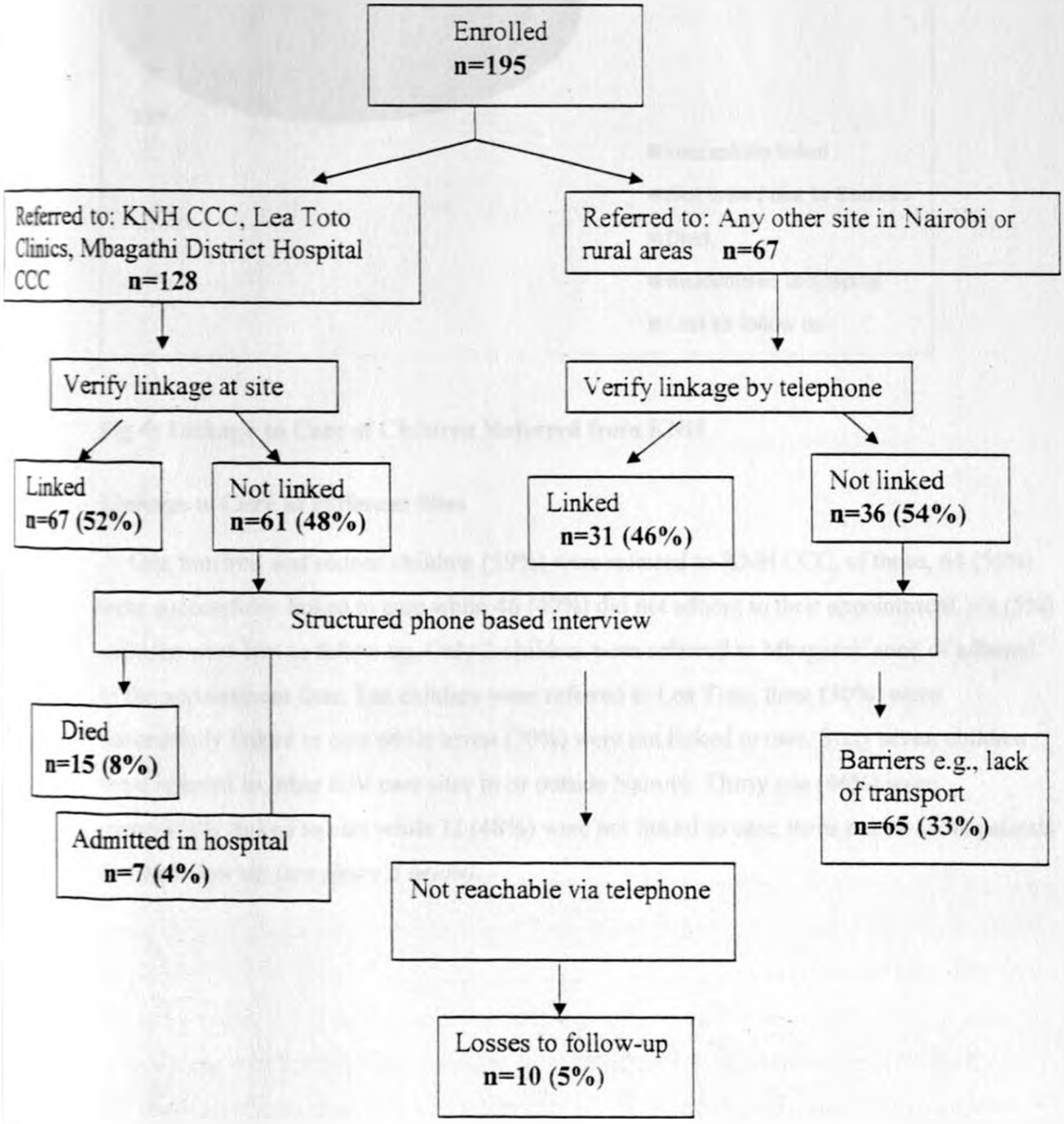

Fig 3: enrolment and linkage to long term care

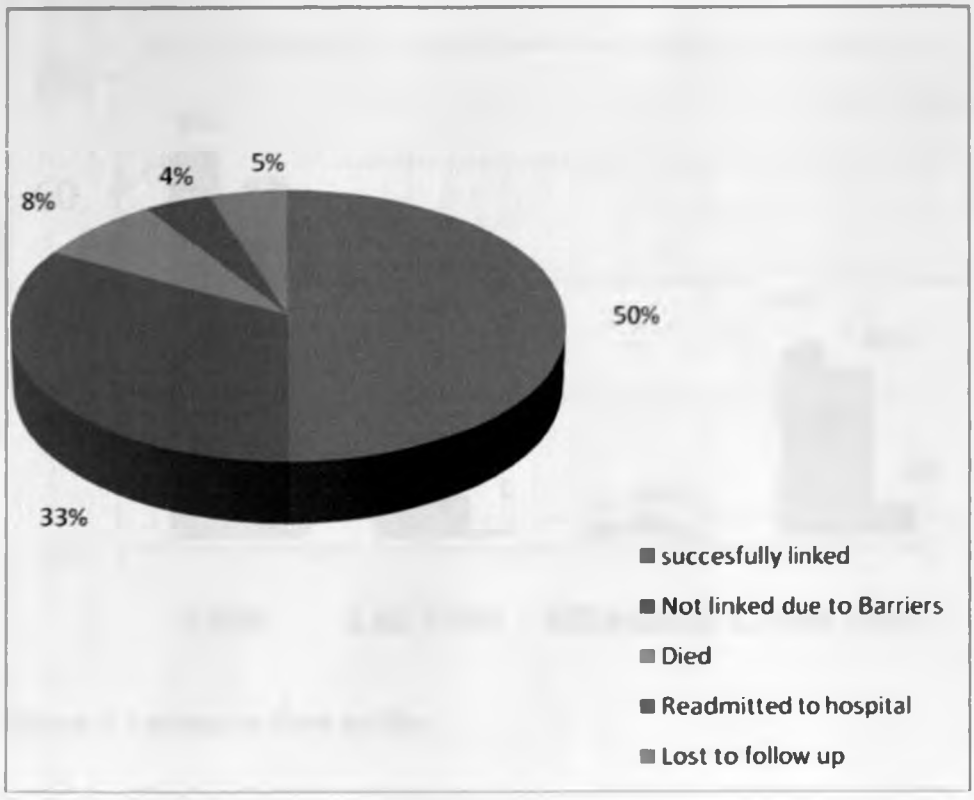

Fig 4: Linkage to Care of Children Referred from KNH

Linkage to Care at Different Sites

One hundred and sixteen children (59%) were referred to KNH CCC, of these, 64 (55%) were successfully linked to care while 46 (40%) did not adhere to their appointment, six (5%) children were lost to follow up. Only 2 children were referred to Mbagathi; none of adhered to the appointment date. Ten children were referred to Lea Toto, three (30%) were successfully linked to care while seven (70%) were not linked to care. Sixty seven children were referred to other HIV care sites in or outside Nairobi. Thirty one (46%) were successfully linked to care while 32 (48%) were not linked to care, there were 4 (6%) patients lost to follow up *(see figure 5 below)*.

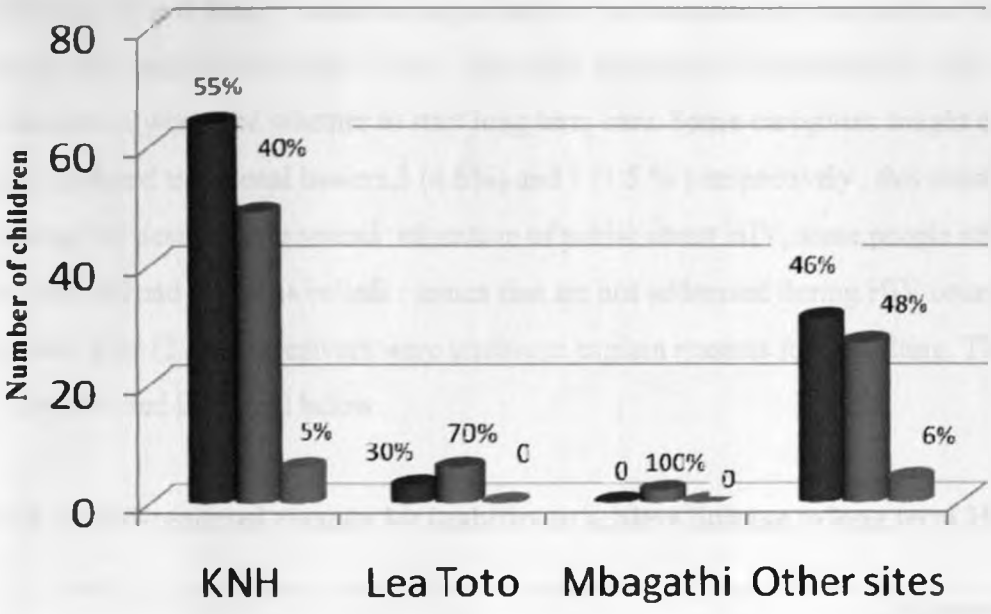

Figure 5: Linkage to Care by Site

Barriers to Care

The analysis of barriers to care reported in the following section includes only the 65 caretakers of children who were not linked to long term HIV care. The caretaker self-reported barriers to completing referral for long term HIV care are listed in table 4 below.

The most common (32.3%) reason for not linking to long term care was nondisclosure of HIV status to spouse or significant others. Mothers reported that the fact that their spouses were unaware of the child's HIV status made it difficult to seek care since health care decisions are commonly made with the knowledge of household heads. Some mothers went on to say that they could not obtain money for transport to from their spouses because they had not informed them of the child's HIV status and hence the need for long term care. In fact, in one case where maternal death occurred before the appointment date the relatives left in charge of the child were unaware of the child's condition or the appointment that had been scheduled to initiate long term HIV care. Unfortunately there were several family disruptions following the revelation of the child's HIV status , this further compromised linkage to care; caregivers abandoned by their spouses or those kicked out of their homes took time resettling in their new residents and hence a delay in linkage to care. Stigma emerged as an important barrier to long term care; 4 (6.2%) of the care takers cited fear of stigmatization by their friends and neighbours as their main reason for non linkage to long term HIV care.

Inadequate counselling of caretakers by health workers also emerged as an important cause of

UNIVERSITY OF NAIROBI
MEDICAL LIBRARY

failed linkage to long term HIV care. Although all the medical records had a referral note indicating site and date of scheduled appointment some caretakers reported that they lacked enough information about their Childs' care after discharge. Four caretakers said they were undecided on when and whether to start long term care. Some caregivers sought care from faith based and traditional healers.3 (4.6%) and 1 (1.5 %) respectively . this possibly explains that despite wide spread education of public about HIV. some people still hold on to their cultural and religious beliefs ; issues that are not addressed during HIV counselling sessions. Two (3.1%) caregivers were unable to explain reasons for defaulting. These results are summarized in table 5 below.

Table 5: Self-reported reasons for inability to achieve linkage to long term HIV care

Perceived barrier to care	Number (n=65)	Percentage
Not disclosed HIV status to spouse or significant other	21	32.3
Lack of money for transport	7	10.8
Relocation resulting in disruption of care seeking	7	10.8
Not informed that the child required follow up in an HIV clinic after leaving the hospital	8	12.2
Undecided on whether to initiate Long term care	5	7.7
Fear of stigma	4	6.2
Parent or guardian sick	3	4.6
Caretaker unavailability due to death	3	4.6
Sought advice/care from faith based Healers	3	4.6
Unable to explain reasons for defaulting	2	3.1
Parent or guardian unable to get time off from work	1	1.5
Sought advice from traditional healers	1	1.5
Total	65	100

Factors Influencing Linkage into Long Term HIV Care

Analysis of the characteristics of the study participants showed significant association of success of linkage to care and the age of the child and caregivers' enrolment to HIV care . Subsequent multivariable analysis for these factors showed that each one of them independently influenced linkage to care significantly ($p<0.05$). Children with at least one parent enrolled on care were 3.8 times (95%CI [1.1.83 to 7.96]) more likely to be enrolled on care compared to those whose caregivers were not on care. Children below on year were more likely to be enrolled on care compared to those aged above 1 year (OR O.47 95%CI [0.25 to 0.87]). See table 6 below.

Table 6: Factors related to linkage to long term care

	Linked to HIV care	Not linked to care	Odds Ratio (95% Confidence interval)	Std. Err.	Z statistic	P value
Age of child (in months)						
Less than 12 moths*	51(56%)	40(44%)	1.00	-	-	-
Above 12 months	47(45%)	57(55%)	0.47(0.25-0.87)	0.15	-2.4	0.016
Parent enrolled for HIV care						
No*	57(41%)	81(59%)	1.00	-	-	-
Yes	33(70%)	14(30%)	3.82(1.83-7.96)	1.43	3.57	<0.0001

*Baseline group

6.0 DISCUSSION

These results indicate that only fifty percent of HIV exposed and HIV infected children are successfully linked to long term HIV care and 33% are not linked due to barriers. It indicates that the high uptake of PITC in KNH paediatric wards [8] is not matched by an equivalent high linkage to care. It indicates that there is indeed a missing link between paediatric HIV diagnosis and long term [10]. It is this disconnect between diagnosis and care that probably explains why the country continues to experience a high mortality from HIV related deaths despite efforts to scale up provider initiated testing and counselling and early infant diagnosis [9]. It possibly further explains why only a few children eligible for ARV's are actually accessing it [29]. Previous reports from CDC indicate that only a quarter of HIV infected persons in the USA are not linked to HIV care [16]. It seems that a higher percentage of HIV infected children are not promptly accessing long term care in our set up. If these findings at the national referral hospital are a reflection on the overall situation in Kenya, then any efforts to scale up PITC should be coupled with a 'linkage to care'package'.

Eight percent of the children recruited in the study died while 4% were hospitalised even before their first appointment to the clinic. This is in keeping with high morbidity and mortality rates seen amongst HIV infected and HIV exposed children demonstrated in previous studies [12]. This short term morbidity and mortality supports the need for prompt linkage of diagnosis to care and early initiation of life saving ARV'S [22].

Barriers to paediatric HIV care seem to relate closely to the family unit; lack of disclosure, disruption of family following HIV diagnosis in a child and poverty among others. Secondly, Lack of enrolment of care giver to HIV care, unknown or negative HIV status of the spouse negatively influenced the success of linkage to care. This simply points to out that paediatric HIV is a disease of the family, therefore 'the family' should be factored in all efforts that target diagnosis and long term care of HIV infected children. Once the diagnosis of HIV infection is made in a child, efforts should be made to engage both parents. This should not only focus on the child's care, but also the caregivers own care and positive living. Caregiver engagement has far reaching effects with regard to subsequent enrolment of the child in to HIV care. These barriers need to be premeditated and addressed during counselling sessions.

Other barriers to HIV care are related to lack of emotional support: care givers of HIV infected children are faced with fear of stigmatization, thus are unable to enrol them into HIV care. One care giver said "I sell fish outside the HIV care centre, if people see me taking my child there, that will be the end of my business which is the source of my livelihood." This

care giver and many others need support on positive living which is indeed a major challenge. The 45 minutes counselling session during HIV testing while useful may need to be backed up with continued counselling even after the child leaves the hospital. This will allow caregivers to air any of their unanswered questions and fears.

While HIV diagnosis and ARV's are provided free to the patients in government and many Non Governmental institutions the service may not be absolutely 'free'. There are hidden costs to accessing care, especially so for children. They have to be accompanied by parents who in addition to paying transport costs also have to forfeit the income generating activity for that day.

Lack of adequate information on long term care emerged as an important barrier. Caregivers seemed to lack information on how soon their children should be enrolled to care and the benefits of long term care. This was surprising because information on care is forms part of the provider initiated counselling package. One would argue that either this information is not adequately emphasised or a positive HIV test result is so distressing that caregivers hardly remember other matters discussed in during the counselling session.

A study in the USA on barriers to care indicated lack of employment and time off work wer the main barriers to care [26] while in our study disclosure and family disruption seemed to be the major barriers to care. Stigma appears to be a common factor in both set ups.

Prompt enrolment to care is crucial to the success of paediatric HIV care. This is because disease progression is rapid among the paediatric age group and therefore, associated with high morbidity and mortality [12].

The study was able to evaluate the success of linkage to care for all patients referred from KNH: this was achieved through verification by site visit and use of telephone. Verification by telephone made it possible to reach out to caregivers to rural areas; an objective that would have otherwise been impossible to achieve. It also provided a chance for answering questions of caregivers and further counselling. Caregivers were impressed with the phone call follow up of their child's progress after leaving the hospital. Some of the care givers who had not enrolled their children to care promised to do so immediately. Verification through site visitation provided a strong confirmation that the child had been linked or not linked to care. The prevalence of success to linkage was comparable for medical record and telephone verification, 55% and 46% respectively.

The study was not without limitations. Caregivers who were not accessible by telephone were excluded from the study. Secondly while the use of telephone was a feasible and

affordable tool, it relied majorly on self report and the risk of over reporting could not be completely ruled out. Thirdly, success of linkage to care was ascertained a week after the expected date of appointment. We were not able to ascertain whether those not successfully linked to care at the time of verification were eventually enrolled to care or not.

The study reveals alarming results of prevalence of linkage to long term care of newly diagnosed HIV exposed and infected children. It clearly shows that there is a missing link between diagnosis and care. Therefore, there is an urgent need to put measures in place to enhance linkage to care after diagnosis. It also shows that paediatric HIV is a disease of the family and lack of family involvement in diagnosis is a major impediment to care. In order to address the problem of linkage to care; restructuring the HIV counselling package is important. This will ensure that both parents are involved during the counselling sessions, there is supported disclosure if one of the parents is not available during counselling and follow up counselling is undertaken when the care giver leaves the hospital.

Conclusion

Only half of newly diagnosed HIV exposed and HIV infected children are successfully linked to long term care. The main barriers to care emanate from the family unit, stigma and inadequate counselling and lack of support to caregivers of these children.

Recommendations

The following are our recommendations:

1. A family focused package for diagnosis of HIV infection in children and subsequent enrolment to HIV care should be developed. This should particularly focus on involving both parents at the time of diagnosis where possible, assisted disclosure to spouse and supportive follow up counselling after leaving the hospital.

2. Decentralize paediatric HIV care services to bring services closer to parents and caregivers of children in order to reduce costs related to travel and time away from work. Programs may consider utilizing mobile clinics.

3. Augment community awareness activities aimed at educating and supporting parents and caregivers of children. This will inform them about paediatric HIV disease and expand uptake of available services for paediatric HIV care. Community interventions should include stigma reduction activities, discouragement of cultural and religious beliefs in the community that prevent people from accessing timely care.

7.0 REFERENCES

[1] Joint United Nations Programme on HIV/AIDS. *2008 Report on the Global AIDS Epidemic*. UNAIDS. Geneva. 2008. p. 33.

[2] UNICEF UNAIDS. WHO. *Towards Universal Access: Scaling up HIV services for women and children in the healthsector* – Progress Report 2008. UNICEF. New York. 2008.

[3] *International epidemiological Databases to Evaluate AIDS (IeDEA) Homepage. Available from http://www.iedea-hiv.org [accessed on 22 April 2009].*

[4] Handbook on paediatric AIDS in Africa. African Network for the Care of Children Affected by AIDS (ANNECA). 2006; 2: 1-11.

[5] Kenya AIDS Indicator Survey (KAIS) – report. 2008; 3-12

[6] Central Bureau of Statistics [Kenya] 2004. *Kenya Demographic and Health Survey. 2003*. Nairobi, Kenya; Calverton, Md., USA. Central Bureau of Statistics: Ministry of Health; ORC Macro.

[7] Obimbo E., Mbori-Ngacha D, Ochieng *Predictors of early mortality in a cohort of Human Immune deficiency type 1 infected African children.* Paeditr Infect Dis J. 2004; 23: 536-543.

[8] Oyieko G. *'Uptake of provider initiated Testing and Counseling in Kenyatta National Hospital pediatrics wards'*, dissertation for M.Med thesis. University of Nairobi. department of pediatrics and child health; November 2006. Unpublished.

[9] Koech. E. 2006. *—Current status of ART in Kenya. Concretizing Pediatrics, Adolescent and Adult ART Scale-up*: 4th National Consultative Conference on Antiretroviral Treatment. Nairobi.

[10] Dorothy Mbori-Ngacha. Irene Inwani . Peter Cherutich . Ruth Nduati. *Optimizing paediatric HIV care in Kenya challenges in early infant diagnosis.* WHO bulletin 2008; 86: 81-160.

[11] Cao. Y.. L. Qin. L. Zhang. J. Safrit. D. D. Ho. *Virologic and immunologic characterization of children with human immunodeficiency virus type 1 infection. N. Engl. J. Med.* 1995: 332: 201-208

(12) Newell. *Mortality in HIV-exposed. uninfected and HIV-infected African children followed prospectively since birth.* Lancet 2004: 364: 1236.

[13] Rouet. F.. Sakarovitch. C.. Msellati. P.. Elenga. N.. Montcho. C.. Viho. I.. Blanche. S.. Rouzioux. C.. Dabis. F.. Leroy. V. *Paediatric Viral Human Immunodeficiency Virus Type 1 RNA Levels. Timing of Infection. and Disease Progression in African HIV-1-Infected Children.* Pediatrics.2003: 112: 289-289.

[14] Guidelines for Prevention and Treatment of Opportunistic Infections among HIV-Exposed and HIV-Infected Children. June 20. 2008. Available at http://aidsinfo.nih.gov/contentfiles/Pediatric_OI.pdf .[Date accessed May 2009]

[15] World Health Organization paediatric ART guidelines for resource-limited settings available at http://www.who.int/hiv/pub/guidelines/art/en/index.html. [Date accessed May 2009]

[16] Ministry of Health-Kenya circular .October 2008

[16] Centre for Disease control: *Estimated number of HIV-infected persons eligible for and receiving HIV antiretroviral therapy, 2003* – United States. Presented at: 12th Conference on Retroviruses and Opportunistic Infections (CROI). Boston. MA. USA. 22–25 February 2005 (Abstract 167).

[18] Marie-Louise Newell . *Mortality of infected and uninfected infants born to HIV infected mothers in Africa*: a pooled analysis. Lancet.2004Oct2: 364(9441):1236-43.

[19] Spira.R. .Phillipe L.. Phillipe V.. Valaren. Simonon. Etaine K. *Natural History of HIV-1 infected and uninfected children: A 5 year prospective cohort.* JAMA. Nov 1999: 104 (5): 56.

[20] Chintu C. Bhat GJ. Walker AS et al. *Co-trimoxazole as prophylaxis against opportunistic infections in HIV infected Zambian children* (CHAP): a double-blind randomised placebo-controlled trial. The Lancet. 2004 Nov 20: 364 (9448):1865-71.

[21] Wamalwa D.. Obimbo E. .Farquhar C. .Mboori-Ngacha D. .Richardson *Adherence and early response to HAART in Kenyan Children.* JAIDS. July 2007: 45(3): 311-317

[22] Violari. Avy. '*Children with HIV Early Antiretroviral Therapy (CHER) Study*'. presentation at the 4th International AIDS Society Conference on HIV Pathogenesis. Treatment and Prevention. Sydney. 22–25 July 2007.

[23] Patel. K.. 'Long-*Term Effects of Highly Active Antiretroviral Therapy on CD4− Cell Evolution among Children and Adolescents Infected with HIV: 5 years and counting*'. Clinical Infectious Diseases.1 June 2008: 46 (11): 1751–1760.

[24] Arrivé. Elise. '*Response to Anti-Retroviral Therapy (ART) in Children in Sub-Saharan Africa*: A pooled analysis of clinical databases – The KIDS-ART-LINC Collaboration'. poster abstract presented at the 14thConference on Retroviruses and Opportunistic Infections. Los Angeles.25–28 February 2007.

[25] Mugavero MJ. Lin H-Y. Allison JJ : *Failure to establish HIV care: characterizing the 'No Show' phenomenon*. Clin. Infect. Dis. 2007: 45: 127–130 .

[26] Heckman TG. Somlai AM. Peters J et al.: *Barriers to care among persons living with HIV/AIDS* . AIDS Care. 1998: 10: 365–375.

[27] Bradford J: *The promise of outreach for engaging and retaining out-of-care persons in HIV medical care*. AIDS Patient Care STDs.2007: 21: 85–91.

[28] Gardner L. Metsch L. Anderson-Mahony P et al.: *Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care.* AIDS.2005:19: 423–431.

[29] Cherutich. P. *Progress in pediatric ART in Kenya. – Concretizing Pediatrics. Adolescent and Adult ART Scale-up*: 4th National Consultative Conference on Antiretroviral Treatment. Nairobi. 2006.

Appendix 1

WHO Clinical Staging of HIV Disease in Children with Confirmed Infection

(Revised in 2006)

Clinical Stage 1. Asymptomatic

- Asymptomatic
- Persistent generalised lymphadenopathy

Clinical Stage 2. Mild symptoms

- Unexplained persistent hepatosplenomegaly
- Papular pruritic eruptions
- Fungal nail infection
- Angular cheilitis
- Lineal gingival erythema
- Extensive wart virus infection
- Extensive molluscum contagiosum
- Recurrent oral ulcerations
- Unexplained persistent parotid enlargement
- Herpes zoster
- Recurrent or chronic upper respiratory tract infections
- (otitis media, otorrhoea, sinusitis or tonsillitis)

Clinical Stage 3. Moderate symptoms

- Unexplained moderate malnutrition or wasting not adequately responding to standard therapy
- Unexplained persistent diarrhoea (14 days or more)
- Unexplained persistent fever (above 37.5°C intermittent or constant, for longer than one month)
- Persistent oral candidiasis (after first 6 to 8 weeks of life)
- Oral hairy leukoplakia
- Acute necrotizing ulcerative gingivitis or periodontitis
- Lymph node tuberculosis
- Pulmonary tuberculosis
- Severe recurrent bacterial pneumonia
- Symptomatic lymphoid interstitial pneumonitis
- Chronic HIV-associated lung disease including brochiectasis
- Unexplained anaemia (<8 g/dl), neutropaenia (<0.5 × 10^9/per litre) and/or chronic thrombocytopaenia (<50 × 10^9 per litre)

Clinical Stage 4. Severe symptoms

- Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy
- Pneumocystis pneumonia
- Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection or meningitis but excluding pneumonia)
- Chronic herpes simplex infection (orolabial or cutaneous of more than one month's duration or visceral at any site)
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Extrapulmonary tuberculosis
- Kaposi's sarcoma
- Cytomegalovirus infection: retinitis or cytomegalovirus infection affecting another organ, with onset at age older than one month
- Central nervous system toxoplasmosis (after one month of life)
- Extrapulmonary cryptococcosis (including meningitis)
- HIV encephalopathy
- Disseminated endemic mycosis (coccidiomycosis or histoplasmosis)
- Disseminated non-tuberculous mycobacterial infection
- Chronic cryptosporidiosis (with diarrhoea)
- Chronic isosporiasis
- Cerebral or B-cell non-Hodgkin lymphoma
- Progressive multifocal leukoencephalopathy
- Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy

Appendix 2

WHO Immunological classification of HIV infected children (Revised in 2008)

HIV –associated immunodeficiency	AGE RELATED VALUES BY CD4 PERCENTAGE			
	<11 months	12-35 months	35-59 months	> 5 yrs
Classification	CD4 percent	CD4 percent	CD4 percent	CD4 count cells/mm3
Not significant	>35%	>30 %	>25%	>500
Mild Immunosuppression	30-35%	25-30%	20-25%	350-499
Advanced Immunosupression	25-29%	20-24%	15-19%	200-349
Severe Immunosuppression	<25%	<20%	<15%	< 200 or <15%

Appendix III

Linkage to Long term Care of Newly Diagnosed HIV Infected and HIV Exposed Children at Kenyatta National Hospital

✓ (Tick) the correct response

1. Patient's details

1.1 Study No.....
1.2 Hospital No.....

1.3 Date of birth (dd/mm/yy) ☐☐ ☐☐ ☐☐

1.4 Age: ..... Years .....Months.

1.5 Gender ☐ Male ☐ Female

1.6 Site enrolled ☐ PEU

☐ TB clinic

☐ Ward 3A ☐ Ward 3B ☐ Ward 3C ☐ Ward 3D.

☐ PMTCT

☐ POPC clinics

1.7 Date of admission/ Date seen ...../...../.....
1.8 Date left the Hospital...../...../.....
1.10 Diagnosis/es at admission .....
.....
1.11 Diagnosis/es at discharge.....
.....

1.12 Previous HIV test ☐ Positive i) RAPID TEST. ii) HIV DNA PCR ☐ Negative i) RAPID TEST. ii) HIV DNA PCR

1.13 Current HIV test ☐ Positive i) RAPID TEST. ii) HIV DNA PCR ☐ Negative i) RAPID TEST. ii) HIV DNA PCR

1.14HIV status ☐ indeterminate status ☐ Infected

1.14 CD4 count i) Absolute. ☐ ii) Percentage ☐

iii) ☐ Not done

1.16Immunological stage

☐ Mild immunosuppression ☐ severe immunossuppression

☐ Advanced immunossuppression ☐ CD4 Count not done

1.17 WHO clinical stage

I. ☐ II.☐. III. ☐ IV.☐

1.18Admitted? Yes ☐ No ☐

1.19 Duration of hospital stay

.....days

.....weeks

.....Months

1.20 Septrin started? Yes. ☐. No☐

Date started...../...../.....

1.21 Anti TB's started? Yes.☐ No.☐

Date started...../...../.....

1.22 ARV's started? Yes.☐ No ☐

Date ARV's started...../...../.....

Regimen.....

1.23 Discharge summary given? Yes ☐ No☐

1.23 Referral note given? Yes☐ No☐

2. Referral centre for follow up

2.1 Name of centre..... .....

2.2 Location.....

2.3 Expected date of appointment...../...../.....

2.4 Other information regarding HIV infection and follow up in the discharge summary (extract from discharge summary)

.....

.....

.....

.....

.....

3. Caregiver Details

3.1 Age.....years

3.2 Relationship to child

☐ Mum ☐ Dad ☐ Grandmother ☐ Grandfather

☐ Auntie ☐ Uncle ☐ Step mum ☐ Step dad

☐ Cousin ☐ Sister. ☐ Brother ☐ Not related ☐ other

3.3 If biological parent. what is the marital status

☐ polygamous marriage ☐ monogamous marriage

☐ Single ☐ Divorced

☐ Separated ☐ Widowed ☐ Other

2.4 If biological parent. what is the HIV status?

☐ Positive ☐ negative ☐ unknown

3.4 If positive are you currently on ARVS? ☐ Yes ☐ No

3.5 If positive . are you on follow up in an HIV clinic? Yes ☐ No ☐

3.6 Mother alive? ☐ Yes ☐ No

a) If deceased. year of death..../...../.....

iv) Attended ANC? ☐ Yes ☐ No

d) HIV test done at ANC? Yes ☐ No ☐

f) HIV status positive at ANC? Yes ☐ Yes ☐ No ☐ Don't know

3.7 Feeding of the child

a) Currently breastfeeding? Yes ☐ No ☐
b) If not breastfeeding for how long?.....
c) Never breastfed? Yes ☐ No ☐

3.8 Father alive? Yes ☐ No ☐

a) If deceased a) year of death.....

b) HIV status of father? Positive ☐ negative ☐ Unknown ☐

c) If positive. is he on HIV care ? Yes ☐ No ☐

3.9 Level of education of care giver

☐ No formal education

☐ Primary completed ☐ Primary NOT completed

☐ Secondary completed ☐ Secondary NOT completed

☐ College ☐ University

3.10 Occupation ☐ employed ☐ unemployed ☐ self employed

3.11 How long have you stayed with the child?

i)..... days
ii).....weeks
iii).....months
iv).....years

3.12 Telephone contact(s) i) Self.....
ii) Spouse.....
iii) Other.....

3.13 Residence in Nairobi? Yes ☐ No ☐

i) Name of Estate.....
ii) Name of area.....
ii) House number.....
iv) Important landmark a) shop.....
b) Building.....
c) Road.....
d) School.....
e) Bus Stop.....
f) Other (specify) .....

v) Vehicles to the area of residence

a) Matatu number/s.....b)Bus number/s.....

4. Adherence to appointment date.

4.1 Verification to be done by

Phone call ☐

Medical record ☐

Appendix IV

Linkage to long term care of HIV exposed and HIV infected children in Kenyatta National Hospital

Structured Phone based questionnaire

Study No.....

Name of the child.....

Name of caregiver.....

Referral centre.....

Expected date of appointment ...../...../.....

Verification of adherence to appointment done by

Medical record ☐ : adherent to appointment? Yes ☐ No ☐

Phone call ☐

1. Salutation & introduction

2. Confirm if speaking to the right person

3. Enquire about progress of the child since the day of discharge. with the following specific objectives :

i) Is the child brought to the clinic on the date of appointment? (if verification is by phone call)

Yes ☐ No ☐

ii) If YES. what HIV care services were offered?

- Septrin started
- Septrin refill
- Baseline investigation
- Nutritional counselling
- Adherence counselling
- ARV's started
- ARV's refill
- TB screening
- Anti TB's started
- Other. specify.....

iii) If **NOT** adherent to appointment, reasons for not turning up for the appointment.

- ☐ Lack of money for transport
- ☐ Parent or guardian sick
- ☐ Parent or guardian unable to get time off from work
- ☐ Forgot the appointment date

- ☐ Not disclosed HIV status to spouse or significant other

- ☐ Lack of information

  - Not informed that the child is HIV infected or Exposed
  - Not informed that the child required follow up in an HIV clinic after leaving the hospital
  - Not informed that enrollment into HIV care should be as soon as possible after discharge
  - Not informed that ARV's are taken for life and require continuous refill
  - Other.....

- ☐ Does not think follow up is necessary:

  reason.....

- ☐ Sought advice/ care from

  - Traditional healers.....
  - Faith based Healers.....
  - Other.....

☐ Preferred to take the child to another centre? Yes ☐ No.☐

If yes. specify.....

☐ Dissatisfied by Services provided.

☐ Other. specify

.....

.....

.....

.....

CONSENT FORM

Dear Parent/ Guardian.

My name is Dr. Mutisya. I am conducting a research study to find out the proportion of newly diagnosed HIV infected and HIV exposed children at the Kenyatta National Hospital are successfully linked into long term HIV care. I would like to include your child as a participant. This will require that I administer to you a questionnaire and obtain your telephone and physical contact. I will also communicate to you in future via your mobile phone to establish if your child is enrolled in to care.

Participation in this study is voluntary and your decision on whether to participate or not will not prejudice your child's care in any way. Strict confidentiality will be observed at all times. I hope that you accept for your child to participate in this study.

Consent

I Mr/Mrs/Miss..... being a person aged 18 years and over. having read/ been explained to the above and in the knowledge that it is voluntary. do hereby give consent for my child to participate in this study.
I understand that I/ my child have the right to withdraw from the research at any time. for any reason. without penalty or harm.

.....

Parent/ Guardian's signature

Date:.....

.....

Investigator's signature

Date:.....

For any questions/ clarification. contact the principle investigator on:
Telephone number: 0720 733358
email address: immaxwn@yahoo.co.uk

UNIVERSITY OF NAIROBI
MEDICAL LIBRARY