THE MAGNITUDE AND FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AMONG CHILDREN ATTENDING THE HIV CLINIC AT KANGUNDO LEVEL FOUR HOSPITAL

A Dissertation submitted in partial fulfillment of Master of Medicine degree in Paediatrics and Child Health of the University of Nairobi

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DECLARATION

I solemnly confirm that this dissertation is my original work and to the best of my knowledge has not been submitted for the award of degree in any other university.

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DEDICATION

I dedicate this thesis to my husband Dr. Paul Bundi Karau and my son Bundi Karau Junior for their unwavering support during the period of study for my Master of Medicine in Paediatrics and Child health.

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LIST OF ABBREVIATIONS

AMPATH	Academic Model Providing Access to Healthcare
ART	Antiretroviral Therapy
CCC	Comprehensive Care Clinic
CD4	Cluster of Differentiation 4
HIV	Human Immunodeficiency Virus
KAIS	Kenya AIDS Indicator Survey
KH	Kangundo Level 4 Hospital
KIDS-ART-LINC	The Paediatric Antiretroviral Treatment Programmes in Lower-Income Countries
LTFU	Loss to Follow-Up
MOH	Ministry of Health
NASCOP	National AIDS and STI Control Programme
PLHIV	People Living with HIV
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
STI	Sexually Transmitted Infections
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organization

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ABSTRACT

Background: Over the past decade, significant gains have been made in enrolment and care of HIV-infected children in Kenya. Their long-term survival depends on lifetime adherence to antiretroviral therapy. African studies have reported high rates of Loss to Follow up (LTFU) among children in HIV care and treatment centres. Factors associated with LTFU may vary across populations and countries. Few studies have been conducted among HIV infected children in care in rural areas of Kenya.

Objective: To evaluate the incidence and factors associated with loss to follow up in a cohort of children aged less than 15 years attending the HIV clinic at Kangundo Level Four Hospital.

Study design: We employed a multi-design approach in which we conducted i) A retrospective cohort study to determine incidence and risk factors for LTFU through abstraction of medical records and ii) A cross sectional survey in which we traced and interviewed caregivers of children LTFU and conducted Focus Discussion Groups of the healthcare workers to gain further insight into factors contributing to loss to follow up.

Methodology: We included all HIV-infected children aged below 15 years who were on follow-up at the HIV clinic at Kangundo Level 4 Hospital between January 2010 and December 2015. We obtained sociodemographic and clinical information from patient files and electronic databases. Caregivers of children who had dropped out of care were traced physically and interviewed using a questionnaire on the status of the child (whether dead, alive), and the reasons for dropping out of care. We conducted focus group discussions among the healthcare givers working in the HIV clinic to evaluate health system factors associated with LTFU. Ethical approval was granted by Kenyatta National Hospital/University of Nairobi Ethics and Review Committee. We calculated period prevalence and incidence of LTFU over the 6 year period before and after physical tracing of those LTFU. We performed logistic regression models to identify factors strongly associated with LTFU. Qualitative data from focus group discussion was transcribed and summarized into main themes manually.

Results: Between January 2010 and December 2015, 261 HIV-infected children were followed up at Kangundo Level 4 Hospital, with 51.3% being males. The mean age was 10.0 years (IQR 7-13), and median CD4 count of 582cells/ul (IQR 314-984). At the time of enrolment into the study, 70 children (26.8%) were in HIV WHO stage I, 115 (44.1%) were stage II, 61 (26.4%) were stage III and 2 children (0.8%) were WHO stage IV. The overall follow up time of the whole cohort was 1003.9 person years with a median of 4 years (IQR1-5).

By December 2015, 171 children (65.5%) remained in active care, 32 (12.3%) transferred out, 13 (5%) died, while 45 (17.2%) were classified as LTFU giving a period prevalence of LTFU as 17.2% and incidence rate 44.9 (95% CI 43 to 47) per 1000 child years.

Out of the 45 children presumed as LTFU, we successfully traced 44 out of the 45 children (98%),and found that their actual current status was as follows: 33 of the 44 children (75.0%) had dropped out of care, hence fulfilled the criteria for true LTFU, 6 children (13.6%) were dead and 5 (11.4%) had transferred themselves to other facilities. The median time for those LTFU was 8 months (IQR 4-34) with a follow up time of 79.7 child years. Following tracing the true period prevalence and incidence of LTFU was 12.6% and 32.9 (95% CI 30.9 to 34.9) per 1000 child years respectively.

Factors strongly predictive of LTFU included male gender (HR 1.22, 1.08-2.63, p= 0.025) low caregiver level of education (HR 2.3, 1.9-3.9, P =0.001), WHO stage I and II at enrolment (HR 1.6, 1.4-2.1, P =0.05) and children not on ART at last contact with hospital (HR 4.7, 4.4-6.0, p=0.03). The factors perceived by healthcare workers to contribute to loss to follow up included stigma, inadequate staffing, poor clinic physical infrastructure and poor attitude of health care workers.

Conclusions: Over the 6 year period, LTFU of HIV infected children was common with an incidence rate of 32.9 per 1000 child years and occurred early in treatment and risk factors included low caregiver education, male child, early HIV disease stage and not being on ART.

INTRODUCTION

The prevalence of HIV in Sub-Saharan Africa remains high, with an estimated 34 million people infected. Of the 2.3 million HIV-infected children, about 90% are in Sub-Saharan Africa making up 10% of People Living with HIV (PLHIV) in the region[1]. Although there has been an encouraging decline in number of PLHIV in Kenya, about 1.6 million people are still infected, with children below 15 years making up 12% [2].

Anti Retroviral Therapy (ART) coverage in Kenya has significantly expanded over the past decade with 78.4% of those requiring ART accessing ART but coverage among children remains low with only 41% of those needing ART receiving it[2]. HIV related mortality among children in Kenya has halved from 22,835 in the year 2000 to 10, 393 in 2013 [2]. The long-term success of ART in children depends on adherence to treatment and follow up. This is critical in children, as they will require life-long therapy[3] without which HIV disease progresses more rapidly than in adults.

As ART coverage expands, a rise in loss to follow-up (LTFU) has been observed in many ART programmes in Africa and is notably worse among children[4]. LTFU is, therefore, a major impediment to successful implementation of HIV care and treatment programmes in Sub-Saharan Africa, with an estimated 20-40% of patients being lost to follow up [4]. LTFU is associated with increased risk of ART failure, morbidity, mortality and hospitalizations[5]. LTFU is a significant clinical and epidemiological challenge, and compromises long term patients' survival.

LTFU among children in Kenya has been largely evaluated in research settings in tertiary referral hospitals and their catchment areas. In a large programme in Western Kenya, 50% of children were found to have ever missed an appointment[6]. According to National Cohort Analysis by Kenya National Aids and STI Control Programme[7], 18% of children under the age of 10 years and 32% of adolescents are LTFU. Eighteen out of every 100 children enrolled in ART programmes in Western Kenya will be LTFU[8]. For those initiated on ART, 14% are LTFU, raising the concern of drug resistance and disease progression.

Several sociodemographic and clinico-immunological factors have been reported to contribute to LTFU among children in ART programmes. Factors associated with LTFU may differ from population to population. A better understanding of these factors will help to develop targeted interventions to improve retention, and predict the risk of LTFU among newly enrolled children so as to institute proper measures on initial contact.

The aim of the present study was to determine the incidence of LTFU, as well as identify the baseline and follow up characteristics associated with LTFU among children enrolled in an HIV care and treatment programme in a rural hospital in Eastern Kenya.

CHAPTER 1

LITERATURE REVIEW

1.1 Epidemiology of Human Immunodeficiency Virus/ Acquired Immunodeficiency Disease in kenya

According to Kenya AIDS Indicator Survey[2], the national prevalence of HIV in Kenya stands at 6%, with 5.6% men and 7.6% women being infected. About 1.6 million people are currently living with HIV. Out of these, 191, 840 are children aged 0 to 14 years, making 12% of PLHIV in Kenya. In the year 2013, the country reported 12, 940 annual new infections in children[2]. It is estimated that annually, 27310, 20765 and 10390 women, men and children respectively die due to HIV. These figures represent a steep and encouraging decline since the year 2000, with new infections among children declining from an estimated 44, 000 in the year 2000 to 12, 940 in 2013. Since 2003, Kenya has seen a significant decline in number of deaths related to HIV, from a high of 167, 000 to 58, 465 in 2013 [2].

The total population of Machakos County in Eastern Kenya, where Kangundo Level 4 Hospital is situated is 1,155,957. Annually, new infections in the country are estimated at 1,463 in adults and 80 among children and adolescents. The total number of PLHIV stands at 31,235 with 4,135 children under 15 years living with HIV. The prevalence of HIV among adult males and females stand at 2.9% and 6.8% respectively. It is estimated that 2953 children living with HIV need ART based on advanced HIV disease[8]. Following the adoption of the rapid advice on use of antiretroviral drugs for treating and preventing HIV infection in June 2014 it is recommended that ALL children less than ten years in Kenya with HIV infection should be started on ART regardless of HIV disease stage and CD4 count. In Machakos county 921 and 177 adults and children respectively die of HIV related causes yearly[8]

Despite these encouraging gains, the war against HIV is far from being won. Sustained action is needed to achieve the goal of “Getting to zero” which is a strategy

targeting zero new infections, zero AIDS related deaths and zero discrimination by the end of the year 2015. The next frontier, therefore, is proper follow up of HIV-infected persons, especially children.

1.2 Loss to follow up of HIV Infected Children

1.21 Definition of Loss to Follow Up

The accurate categorization of patients as either active or LTFU presents unique challenges. Different definitions of LTFU have been employed in various studies in different countries. There is therefore the inherent risk of misclassification of active patients as LTFU. This lack of standardization of the definition of LTFU across studies precludes formal meta-analysis of these data. Data from one study may not be extrapolated into another population because of these different definitions.

Many ART programmes have used a 6 month absence from the HIV clinic to define LTFU[10]. Other thresholds have been considered. For instance, Kenya's AMPATH programme (Academic Model Providing Access to Healthcare) defines LTFU as 3 months of absence from the HIV clinic since the last encounter[11]. In other studies, LTFU has been defined as missed appointments. Deribe et al., (2008)[12] used a threshold of more than 2 weeks, Dilal et al., (2008)[13] employed a threshold of more than 6 weeks of missed appointments among a South African Cohort, while Bison et al (2008)[14] used a threshold of missed appointment for more than 1 week in a Botswanian study.

A systematic review and pooled analysis of various definitions of LTFU recommended a threshold of 180 days since the last clinic encounter as the standard definition[15].

The World Health Organization defines LTFU as more than 90 days from the missed clinical or drug pick-up appointment without any follow-up contact[16]. The National AIDs and STI Control Programme (NASCOP, Kenya) uses a definition of more than

3 months since the last clinic encounter. This has been incorporated into the tools used in patient evaluation and monitoring in the HIV clinics in the country.

1.22 Magnitude of Loss to Follow Up

In developing countries, HIV care and treatment programmes have rapidly expanded over the past decade. The success of these programmes depends on regular patient follow-up, monitoring and evaluation. Overall, it is estimated that 21% of patients in HIV programmes are lost to follow-up 6 months after starting ART[10]. Most studies in Sub-Saharan Africa have reported 20-40% incidence of LTFU among patients at all levels[4]. This incidence varies with the definition of LTFU in the various studies.

The magnitude of LTFU among children varies between populations, as well as between age-groups of children. For instance, LTFU among HIV-exposed infants was found to range from 4.1%-68.1% in a systematic review. In Brazil, among 1200 children included in a study in Pernambuco, the incidence of LTFU was found to be 15.4% [21]. The magnitude of LTFU among children in various study cohorts is summarized in table1 below

Table 1: Studies on loss to follow up

Author, year	Country/ Setting	Age (months)	No. of patients	% LTFU
Ahoua et al., 2010[24]	Uganda, rural	0-18	567	50.1%
Sherman et al., 2004[25]	South Africa,urban	0-12	1907	50.2%
Manzi et al., 2005[26]	Malawi, rural	0-6	206	68.1%
Sam et al., 2003[22]	United Kingdom, Urban	0-12	104	26
Ferguson et al., 2011[23]	Ireland, Urban	0-3	964	4.1%

Studies have highlighted differences in LTFU between children before and after initiation of ART. Pre-ART LTFU was found to be 10-20% at 1 year of follow-up[28], compared to 1.9-4.2% for those on ART. Most LTFU occurs immediately after enrolment. Teasdale *et al* (2012)[29] reported that 29.3% of children in a Mozambican cohort were LTFU six months after enrolment. The KIDS-ART LINC collaboration[30] reported a trend of increasing LTFU over time, in an analysis of 16 paediatric HIV care programmes in low income African countries. The risk of LTFU was 2.8% at 6 months, 4.6% at 1 year, and 8.4% at 2 years[30]. The authors called for caution in interpreting this data, because they did not estimate how much of LTFU was due to unreported deaths, and to which extent the true mortality rate was underestimated. In a South African study, 7.6% of children were lost to follow up in the first year of ART. This incidence was highest in the first 3 months of ART, with a period incidence rate of 13.5 per 1000 child-years. The overall incidence of LTFU in the 2nd year was 5.0 per 1000 child-years[31]. In a Western Kenya study, over 50% of HIV-infected children missed at least one scheduled clinic visit, with 40% of the children missing at least 1 in 10 scheduled clinic visits[6].

Review of the existing literature on the magnitude of LTFU therefore illustrates that there are stark population differences, and that data from one population or country may not be necessarily applicable to another population.

1.23 Loss to Follow Up among HIV Infected Adults

The factors associated with LTFU among adults appear to be similar to those among children as evidenced by many studies. A combination of clinical, sociodemographic and healthcare related factors contribute to LTFU. Poor nutritional status, lower CD4 count, Tuberculosis (TB) co infection, advanced clinical staging, younger age, adverse drug reactions, gaps in services, and accessibility to services are some of the predictors reported to be associated with LTFU[11]. Marital status also influences LTFU. In a South African study, being married or cohabiting was associated with higher incidence of LTFU compared to single or divorced adults (Peltzer et al.,

2011). Children have to depend on caregivers for their clinic appointments, and are therefore more likely to be LTFU. However, there's little or no literature comparing LTFU between children and adults. Table 2 below shows LTFU among both children and adults.

Table 2: Loss to follow up among both adults and children

Author/ year	Location	Setting	LTFU definition	Age of patient	No of patients	%LTFU
Yu et al, 2007[17]	Malawi	Rural	No visit > 3 months	Adults and children	5009(403 i.e.8% children<15 years)	5.0
Dalal et al, 2008[13]	Johannesburg, S. Africa	Urban	Missed appointments >6 weeks	Adults	1631	16.4
Krebs et al, 2008[18]	Lusaka, Zambia	Urban	Missed > 1 week	adults	1343	21.0
Bisson et al, 2008[14]	Gaborone, Botswana	Urban	Missed >30 days	adults	410	16.6
Geng et al, 2008[19]	Mbarara, Uganda	Rural	Missed > 6 months	adults	3628	22.9
Deribe et al , 2008[12]	Jimma, Ethiopia	Urban	Any missed appointment	Adults and children	1270 (55 i.e. 4.3% children <15 years)	28.0
An et al 2009[20]	Eldoret, Kenya	Urban & rural	Any missed appointment	Adults	8977	39.3

1.24 Factors Associated with Loss to Follow up

A profile analysis of LTFU among children may help to understand the problem and provide an insight on how to address it. Knowledge of the factors associated with LTFU has potential utility in making recommendations for patient retention in Paediatric HIV care programmes. Further, knowing the factors leading to LTFU may provide unique opportunities for early intervention, in an effort to bolster retention in HIV programmes and improve overall outcomes of these children.

Various authors have documented several reasons for LTFU. These factors are composite in nature, with some involving the children themselves, the caregivers, the family structure and society, and the health care systems. No single factors appear to be replicated across the board due to differences in culture and approaches by various HIV programmes across the African continent. Some of the factors that have been linked to LTFU are discussed below.

i. Sociodemographic Factors Predictive of Loss to Follow Up

Children-related sociodemographic factors leading to LTFU have been described in various studies in Sub-Saharan Africa. In a study in Mozambique, Teasdale et al (2012)[29] found that younger children (2-3 years) are more likely to be LTFU compared with older children. Similar findings were reported in a South African cohort, which reported that older children were less likely to be LTFU compared to infants and younger children[31]. The KIDS-ART-LINC study found that in many Sub-Saharan African countries, the probability of LTFU in children on ART is 9.5% and 19.2% at one year and at two years of treatment respectively[30].

While the reasons for this observation have not been elucidated, it is possible that children face the unique challenge of being unable to decide on their own, as well as being taken care of by mothers, who may also be suffering from HIV.

Male children are more likely to be LTFU, according to many studies in the literature. This has been reported by researchers in South Africa[31], Uganda[32] and the KIDS-ART-

LINC collaboration study (2008)[30]. Another study done in Uganda reported a higher incidence of LTFU among female children compared to males, although the difference was not statistically significant[33].

Care-giver factors have also been heavily linked with LTFU. In Africa, most HIV-infected children are orphans, raised by grandmothers and other older siblings[30]. These care takers often have little or no formal education, as well as meager financial resources to fend for these children. Caregivers of children with low education levels were more likely to be LTFU in Pernambuco, Brazil[21]. Additionally, some children are forced to change caretakers and relocate to different homes when they are orphaned, making follow up difficult and leading to LTFU. Surprisingly, several studies report that children whose biological mothers are the primary caregivers are more likely to be LTFU[31, 32]. In a research conducted in Western Kenya, Braitstein *et al* (2010)[8] found that orphans and older children were less likely to be LTFU. Some of the possible explanations for LTFU among children raised by their mothers include; the mother may be too ill, often suffering from HIV, the mother may have died or may be suffering from guilt, considering that most of these children are infected through vertical transmission from infected mothers. Further, maternal use of alcohol and illicit drugs has a positive correlation with LTFU.

A prospective observational study entitled *wamepotea* in Western Kenya reported that a significant number of children are LTFU because caregivers fear stigmatization from society, while others believe that the child was healed by faith or from use of traditional medicine[35]. Others are victims of family conflict, commonly brought forth by the diagnosis of HIV, or displacement due to clashes and social strife. Given the disparate cultural practices among different communities, studies need to be conducted in several areas to further strengthen this finding.

Distance from home to the health facility has also been found to influence LTFU, with children coming from remote areas more likely to be LTFU. An African qualitative study identified transport to a centralized HIV care facility as a burden in rural areas (Bwirine et al., 2008). This is compounded by financial constraints[3].

ii. Clinical Factors Predictive of Loss to Follow up

Malnutrition has been positively linked with LTFU among children. Teasdale et al (2012)[29] reported that severely malnourished children are 1.23 times more likely to be LTFU. Cachexic children have been found to be 3 times more likely to be LTFU than well-nourished ones[31]. Children who are more than two standard deviations (-2SD) less than the weight-for-age and weight-for-height which is one of the AIDS defining signs have been associated with LTFU[33] .

LTFU is attributable to severe immunosuppression[33]. Massavon *et al* found a hazard ratio of 4.17 risk of LTFU among severely immunosuppressed children in Uganda compared to those with no significant immunosuppression. The KIDS-ART-LINC study[30] also confirmed a positive correlation between LTFU and severe clinical status defined as HIV WHO stage 3 or 4 and/ or a weight for age Z score <-3.

In an Ethiopian study, Berheto *et al* (2014)[34] reported that children with baseline CD4 counts less than 200cells/ul are more likely to be LTFU compared with baseline CD4 count over 200cells/ul. Further results suggested that treatment failure may be associated with a higher likelihood of LTFU. Patients who made a regimen substitution had 5.1 times more risk of LTFU. However, some studies have found higher LTFU rates among children in WHO clinical stages I and II compared to III and IV[29] in Mozambique, which may be attributable to the caregiver notion that such children are not sick. This is discordant to the findings in Uganda by Massavon et al (2014)[33] that children in WHO stages III and IV were more likely to be LTFU.

Most LTFU has been reported in the immediate period after enrolment into care and treatment. Research done in Mozambique found that LTFU is significantly higher in the first 6 months after enrolment compared to 1 year and 2 years later[29]. Further, treatment for pulmonary tuberculosis[34] and severe anaemia[30] are linked with higher incidence of LTFU. One challenging fact is that little is known about the children who get LTFU, as there's little research on physically contacting these children. Among adults, about 50% of those LTFU will be deceased. The finding that most children are LTFU in

the immediate post-enrolment period, or when on TB treatment or are severely anaemic raises the possibility of death of severe infirmity as the main reason for LTFU.

iii. Health System Related Factors that impact Patient Retention in Care

Disclosure of HIV status to children remains a challenging prospect, with no universally agreed on timeline as to when children should be told about their status. Many healthcare workers are not willing to disclose to children, and this may have an impact on LTFU[35]. Further, missing patient records and poor defaulter tracing may misclassify some patients as LTFU when in fact they are not.

Studies done within the Academic Model for Provision of Access to Healthcare (AMPATH) in Western Kenya report that giving food supplements to children discourages LTFU[36]. This brings to fore the need to add ancillary interventions to promote health and wellbeing, such as food rations, adherence counseling and psychosocial support.

JUSTIFICATION

Without early and continuous ART, HIV infected children experience rapid progression of the disease and high mortality. Massive resources have been used in implementing HIV care programmes in Kenya. With the expansion of HIV care and treatment programmes in the country, the next frontier in the fight against HIV remains delivery of quality care and retention of patients in care.

The magnitude of LTFU in African children has been reported mainly from studies done in urban research settings. This observed poor retention in care threatens to reverse the gains made in the past decade, and retard the achievement of UN AIDS target of '90%'. The country and Africa at large needs sustained action for "Getting to Zero" [7]

Despite the importance of retention in care for long term survival, there remains a knowledge gap on the magnitude and factors associated with LTFU in rural settings in Africa. Some of these factors may be specific for populations and their ethnicities, so that studies conducted elsewhere may not be necessarily applicable to these populations.

Given the knowledge gap of LTFU in rural settings in Kenya and the poor outcomes associated with LTFU, it is with this background that we proceeded to evaluate in a rural setting in Kenya, magnitude and predictors of dropping out of care of HIV infected children. We anticipate that insights gained shall be valuable to inform interventions to optimize retention in HIV care programs in rural settings.

CHAPTER 2

OBJECTIVES

Broad objective

To determine the magnitude of loss to follow up and associated factors among HIV infected children aged below 15 years attending HIV clinic between January 2010 and December 2015 at Kangundo Level 4 Hospital

Specific objectives

i. To determine the incidence of loss to follow up among HIV infected children attending HIV clinic over six year duration at Kangundo Level 4 Hospital.
ii. To describe the factors associated with loss to follow up among HIV infected children attending HIV clinic at Kangundo Level 4 Hospital. Factors of interest include sociodemographic, clinical and health system factors
iii. To describe health workers perceptions on the factors contributing to Loss to follow up among HIV infected children on care at Kangundo Level 4 Hospital

CHAPTER 3

METHODS

3.1 Study Design

We employed a multi-design approach in which we conducted

i. A retrospective cohort study to determine incidence and risk factors for LTFU through abstraction of medical records and
ii. A cross sectional survey in which we traced and interviewed caregivers of LTFU children and conducted Focus Discussion Groups of the healthcare workers to gain further insight into factors contributing to loss to follow up.

3.2 Study Setting

The research was conducted at Kangundo Level 4 hospital situated in Kangundo sub-county in Machakos county serving a population of approximately 250, 000 people. The hospital is situated in lower Eastern part of Kenya, about 60km east of Nairobi. Most people living in the region are Kambas whose main occupation is small scale farming and livestock keeping. About 25%- 35% of the population is unemployed with 56% of them living below the poverty line according to the Kenya National Bureau of Statistics (KNBS 2013) and Society for International Development (SID), 2013).

Kangundo Level 4 Hospital is a high volume hospital that provides both inpatient and outpatient services for both children and adults. It has a daily patient turnover of 200 patients half of whom are children. According to the hierarchical organization of the Ministry of Health in Kenya, health care facilities are categorized from level 1 to 6, with the first level being those at the community level, while level 6 hospitals are the topmost referral centres.

Kangundo Level 4 Hospital runs a HIV clinic that was started in 2005. Currently, approximately 3500 patients are enrolled, approximately 300 of them being children below 15years. The HIV Clinic is headed by a medical officer. The other personnel

working in the clinic include a nurse, one pharmacist, one health records officer, three peer educators and two lay counselors. Patients are usually attended to by the medical officer in-charge assisted by other medical officers and clinical officers working in the hospital on rotation basis. There are a total of 5 medical officers and 10 clinical officers in the facility. All of them have had training on HIV during the Continuous Medical Education sessions held at the hospital every Wednesday.

The physical infrastructure of the clinic includes the records room where patients' files are kept in an organized manner, the counseling room where the nurse and one of the peer counselors do patients' counseling and take anthropometric parameters of patients before sending them to the consultation rooms. The clinic has two spacious consultation rooms. Once the patients are reviewed by the clinicians, they are sent to the pharmacy to collect their medication and then back to the records room to get the next clinic appointment date.

Patients' records are kept in two forms, the hard copy files and the electronic medical record. Most documentation for the patients who visit the clinic with no presenting complaints is in structured form. For the patients who are unwell, the clinician usually fills the structured forms and uses unstructured continuation forms to document comprehensive history, physical examination and plan of management for the patient. The Electronic Medical Record is done at the pharmacy during refill of drugs and at the health records room where data in the patients' physical file is updated in the computer at the end of each clinic day.

The clinic runs every Monday to Friday from 8 am to 5 p.m. All the services provided in the clinic are free of charge. The paediatric clinic runs every Thursday from 8.00am to 5.00pm. On average about 20- 30 patients are reviewed each clinic day. During the clinic visits, health talks are usually given. The children are provided with mid morning snacks as a form of incentive. Only children with a confirmed HIV diagnosis confirmed by either DNA PCR (those aged below 18 months) or rapid HIV tests for children above 18 months of age are followed up in the clinic. An HIV confirmatory test is always done before enrolment into the clinic. The other baseline tests done are CD4 count and/or CD4%, full haemogram and creatinine. For monitoring of patients, CD4 count or CD4 % is repeated six monthly. Viral load is only done for patients suspected

to have treatment failure. Patients with confirmed treatment failure are usually changed to 2nd line Anti retroviral Therapy. At enrolment, most patients are started on septrin prophylaxis.

Patients who miss their clinic appointments are usually entered in the defaulter tracing register. The register captures, name and clinic number of the patient, whether on ART or not, clinic enrolment date, date of missed appointment, client's telephone number and physical address, clients' treatment supporter and contact, type of tracing done and outcome. Patients who miss appointments are contacted by the peer educators by phone the following day, if they still don't come; they are contacted again after one week then monthly. If they still don't turn up, after 3 months, they are categorized as LTFU. Currently no routine physical contact tracing is done because of financial constraints.

3.3 Study Population

Inclusion Criteria

All HIV-infected children aged below 15 years attending the Kangundo District Hospital (KDH) clinic, who were on follow-up in the HIV clinic between January 2010 and December 2015 were enrolled into the retrospective medical abstraction part of the study.

For cross- sectional survey, caregivers of all the children categorized as LTFU who consented were recruited into the study.

All health care providers working in KDH HIV clinic who consented for the Focus Discussion Group were included.

Exclusion Criteria

We excluded children whose HIV status was not confirmed and documented and those who had no further follow up visit beyond the enrolment visit.

3.4 Case Definitions

HIV Infection

HIV infection was defined as a positive DNA PCR in children less than 18 months and a positive rapid HIV test in those more than 18 months as per the hospital records.

Loss to Follow up

LTFU was defined as patients who did not return for care or treatment for a period of 3 months or more since their most recent documented appointment date despite repeated phone contact as per NASCOP definition. For patients with multiple episodes of LTFU the latest event was the only one considered.

3.5. Sample Size Determination

We included all children ever enrolled in care over the period of January 2010 to December 2015 who met the inclusion criteria. The cumulative number of children ever enrolled in care at Kangundo District Hospital was 282 out of whom 21 were excluded from the study. Precision of the study was then calculated using Fischer's formula as shown below

$$N = \frac{Z^2 P (1-P)}{d^2}$$

N= available sample size =261 for KDH

z= confidence interval (95%) = 1.96

p=8.8 (incidence estimation of LTFU using an Ethiopian study-predictors of loss to follow up among people living with HIV/ AIDS)

We then used the above estimates to determine achievable study precision

$$261 = \frac{1.96^2 \times 0.088(1-0.088)}{d^2}$$

d= 0.0344

We therefore anticipate that given a fixed number (N) of 261 children and an estimated incidence of 8.8 we are 95% confident that we will be able to determine true incidence rate of LTFU with a precision of 0.0344

For healthcare workers Focus Discussion Group we included all consenting health workers.

3.6 Study Procedures

The research assistants consisted of one nurse, 3 peer counselors and one health records officer working in the HIV clinic. They were trained by the chief investigator for a minimum of three days on the scope of the study, use of case record forms and questionnaires and ethical aspects of the research. The health records officer and the peer counselors assisted in retrieving the files. The nurse and the records officer assisted in filling the case record forms. Peer counselors assisted in contacting those LTFU on phone and physically. The chief investigator was involved in filling of the case record forms, in conducting focus group discussion of the health care workers, obtaining consent from healthcare workers involved in the focus group discussion and tracing and obtaining consent from caregivers whose children were categorized as LTFU.

Retrieval and Abstraction of Medical records of Children

The electronic medical records and the physical files of the patients were used complementarily. Where both hard copy and electronic data was available, the paper based record was used.

Physical files of all children under care in the HIV clinic between January 2010 and December 2015 were retrieved from the records office by the records officer assisted by the peer counsellors. After retrieval, each file was assigned a study number. In addition, a master study register containing the list of patient's hospital name and the assigned study number, phone contact and physical address were set up. This master study register was crucial during tracing of those categorised as LTFU. This register was kept securely by the Principal Investigator. The study number allocated to each file appeared on the corresponding case record form. No hospital patient

identifiers (Hospital number or patient's name) appeared on the case record form. For each patient's case record form, only their study number appeared.

Case record forms were used to capture data from the patients' records(see appendix III). The data collected included the following:-

A. Enrolment or baseline characteristics of the child and caregivers
    a. Sociodemographic characteristics:- year of enrolment, age, gender, caregiver of the child and relationship with the child, educational level, HIV status of the caregiver, whether biological parents are alive or dead and economic status of the parents or caregiver
    b. Baseline Clinical variables:- baseline CD4 count , WHO stage at enrolment, weight , ART regimen initiated and opportunistic infections at enrolment.
B. Follow-up variables (using the last available appointment attended)- Date of last visit, last visit CD4 count, last visit weight , total number of hospitalisations, history of treatment for tuberculosis, history of ART regimen switch and reasons for switch and any adverse drug reactions.

Tracing of children LTFU and interview of caregivers

The Case record forms of all patients categorized as Lost to follow up were grouped together and their study numbers recorded. The patient identifier details (name of patient, name of caregiver, phone number and physical address) were then obtained from the master register to enable tracing by phone or physically. Attempt was made to trace the caregivers of all the patients categorized as LTFU by phone calls. Those who responded to the phone call were informed about the study and requested if they could come to Kangundo level 5 Hospital or allow home visit. For those with no available phone contact, attempt was made to trace them physically guided by the peer counselors. Arrangement was made on day and time of meeting with the principal investigator. During the meeting on the agreed day, the principal investigator explained the purpose, the procedure, the benefits and any risks of the study and allowed the caregiver to give informed consent voluntarily.

The consent was in written form on a pre-designed consent form in English and Swahili language (see appendices I and II). The investigator ensured that the caregiver understood all the information given in the consent form. Where necessary the investigator and research assistants helped in translating the consent form into the caregiver's native language. Any questions and concerns regarding the study by the caregivers were addressed fully before signing the consent. No coercion was used in signing the consent, it was entirely voluntary.

The caregivers who accepted to take part in the study signed the consent form and the principal investigator countersigned the consent form. A copy of the consent form was given to the caregivers who consented to the study.

Data were collected from the caregivers by administration of a structured pre-tested questionnaire (See appendix IV). Each questionnaire was assigned a study number. No patient or caregiver identifier was used. The principal investigator and the research assistants helped in translating the questionnaire in a language they could understand. The status of the patient follow up was then reclassified as transfer out, dead or true LTFU. Figure 1 below shows the procedure for abstraction of medical records and tracing of those lost to follow up.

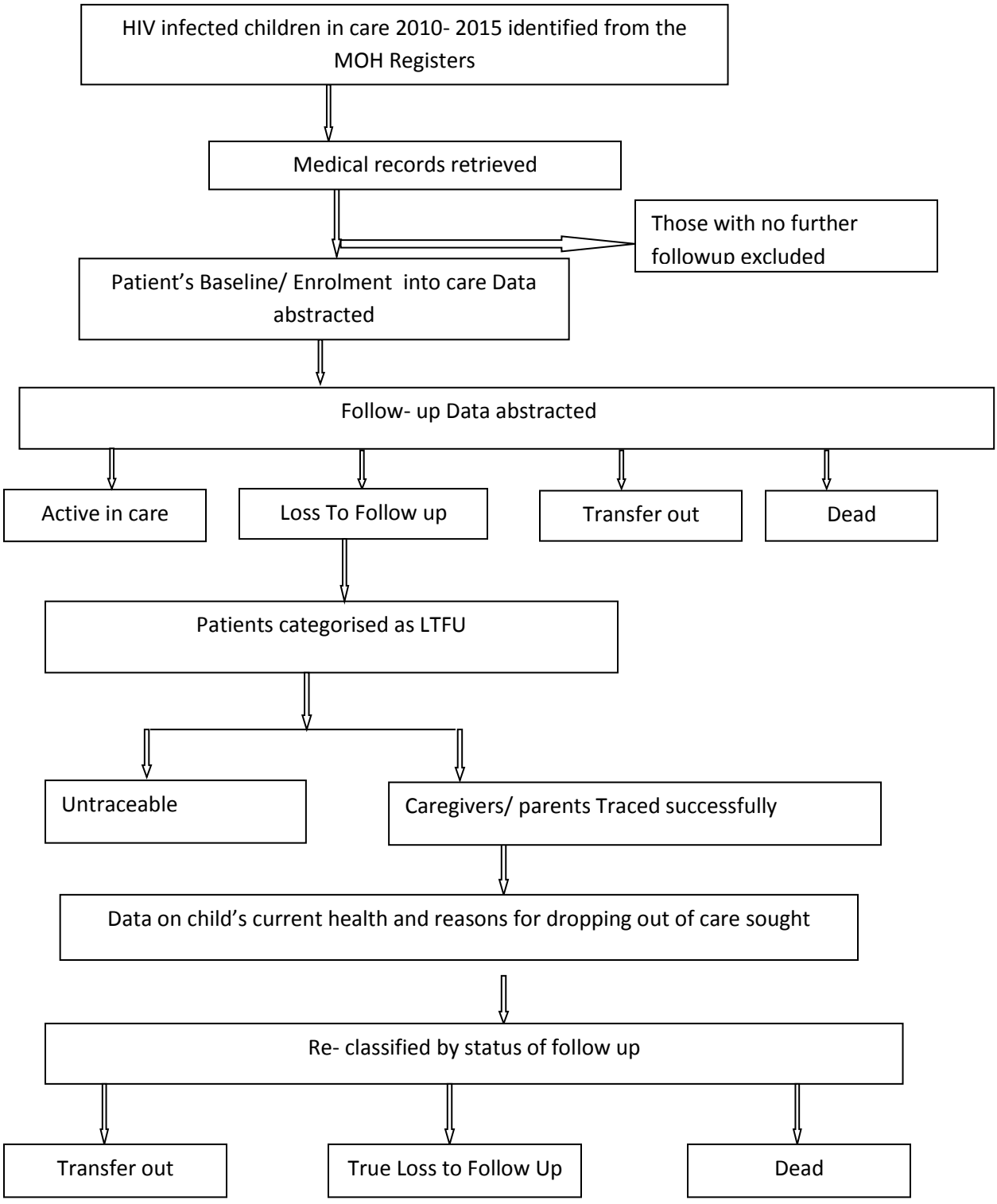

Figure 1: Flow chart showing procedure for abstraction of medical records of children and tracing of those lost to follow up

Focus Discussion Group (FDG) of Health Care Workers

We approached all health care providers working in the HIV clinic at Kangundo Level Four Hospital. Those who consented to participate in the Focus Discussion Group were recruited consecutively. The FDG was conducted in two sessions with 7 and 6 participants respectively. The first session comprised of 7 peer educators of whom 3 were males and 4 were females. All were aged between 40 to 60 years. The second session comprised of 4 female nurses, one male clinical officer, one female pharmacist and one male medical officer. The nurses were aged between 45 and 60 years. The other clinicians were in their early thirties. Each session was conducted over duration of 60 to 90 minutes. The sessions were conducted on 21st and 22nd of December 2015.

The principal investigator was the moderator of the discussions. The sessions were tape recorded and handwritten by the research assistant verbatim. The assistant also noted the participant's facial expressions. Before the discussions the participants were served with food. They made name tags and indicated their preferred names. The principal investigator introduced the topics to explore the health worker's perceptions on reasons for LTFU and possible solutions. The main themes for discussion included: - Socio –economic factors influencing LTFU and the health system factors associated with LTFU.

The discussions were conducted in English and Swahili languages. The principal investigator ensured that the group members participated in natural discussions amongst themselves. Each participant had an opportunity to give his or her views without interruptions. After each session, the Principal investigator and the assistant listened to the audio tapes and re- constructed the contents of the discussions. The Focused Discussion Group guide is as shown in appendix V.

3.8. Data Analysis

Data from the questionnaires were initially entered into excel datasheets and cleaned. It was then exported to SPSS Version 23.0, IBM where coding was done. We created a password protected file in SPSS to protect data before analysis.

Descriptive statistics of patients and caregiver characteristics were determined. Period prevalence of LTFU from KDH was computed as number of children who dropped out of care over the 6 year period divided by total number of children on followup at date of data abstraction and converted into a percentage. The incidence rate was calculated by first determining the sum total time contributed by each child in the study, that is, total child years. The cases of LTFU were determined. The incidence rate was calculated as number of children who dropped out of care over the 6 year period divided by the total child years multiplied by one thousand. The incidence rate was reported as x per 1000 child years.

Among the subset of LTFU from KDH, after tracing a true LTFU was computed by subtracting children who were in active care elsewhere and those who had died. This figure was used as the numerator in calculating the true period prevalence and the true incidence rate. Kaplan Meir survival analysis was used to show the proportion of children retained in care over the 6 year period.

Univariate predictors of LTFU versus retention in care were then determined using Chi-square, Fisher's exact test for categorical or grouped variable and reported as hazard ratios with significance set at 5%($P<0.05$). we then performed a multivariate logistic regression analysis with inclusion of independent variables which had been found to be significant in the univariate analysis with p values <0.03. LTFU was the independent variable while various sociodemographic and clinical characteristics were the dependent variables.Data was presented in tables, graphs and charts. Qualitative data from the Focus Discussion Group of the healthcare workers were transcribed and summarized into main themes manually.

3.9 Ethical Considerations and authority

Ethical approval was sought from the University of Nairobi/Kenyatta National Hospital Ethics and Review Committee.

The purpose of the study was carefully and clearly explained to health care providers working in the HIV clinic and the caregivers of children categorized as Lost to follow up if successfully traced. Informed written consent was obtained.

Strict confidentiality was observed throughout the entire period of the study held in trust by the participating investigators, research assistants and study institutions. Study participants were given study identification numbers and no personal identifiers were used.

Caregivers of children LTFU traced successfully got benefits such as education on importance of their children being on regular follow up so as to make informed choice of continuing with care. We encouraged caregivers to have their children return to care.

Authority to use the Kangundo level 4 Hospital HIV clinic was sought from the Management Board of Kangundo Level 4 Hospital and the county of Machakos medical committee.

CHAPTER 4: RESULTS

4.1 Baseline Sociodemographic Characteristics of the Children

Between January 2009 and December 2015, a total of 261 children were found to be on follow-up at the HIV clinic at Kangundo Level 4 Hospital. The mean age of the children was 9.98yrs, median 10 years (Interquartile range 7-13) with 57.1% (149) and 42.9% (112) males and females respectively. The mother was the primary caregiver for majority of the children (134, 51.3%), followed by grandmother (51, 19.5%). 239 (91.6%) of the children were schooling. Table 3 summarizes the baseline sociodemographic characteristics of the children.

Table 3: Baseline Sociodemographic Characteristics of Children on Follow up at the HIV Clinic, Kangundo Level 4 Hospital

Characteristic	Frequency	%
Age Group		
<2 yrs	5	1.9
2-5 years	37	14.1
6-10	73	28
11-14	146	56
Median age	10	IQR(7-13)
Gender		
Male	149	57.1
Female	112	42.9
Year of enrolment		
Before 2006	29	11.1
2007-2008	56	21.5
2009-2010	74	28.4
2011-2012	53	20.3
2013-2015	49	18.8
Child in school		
Yes	239	91.6
No	20	7.7
Missing data	2	0.8
Biological mother alive		
Yes	131	50.2
No	127	48.7
Missing information	3	1.1

4.2 Baseline clinical characteristics of children

The median CD4 count among the entire cohort of enrolled children was 582 cells/ul. Majority (84.7%) were on ART, with 46.7% (122) on an abacavir-based regimen. Among children LTFU, the median CD4 count was 636.5cells/ul. Majority of the children had weight for age Z score of <-1 to -2 (48.3%). Table 4 summarizes the baseline clinical characteristics of the cohort.

Table 4: Baseline clinical characteristics of the entire cohort of enrolled children

Clinical characteristic	All children enrolled in the clinic	
	N	**%**
WHO stage at enrollment		
Stage I	70	26.8
Stage II	115	44.1
Stage III	69	26.4
Stage IV	2	0.8
Baseline CD4 count	Median	IQR
	636.5	314- 984
Weight: WAZ		
0 to -1	107	40.9
<-1 to -2	126	48.3
<-2 to -3	33	12.6
<-3	2	0.7
Whether on ART		
Yes	221	84.7
No	33	12.6
First line ART regimen		
Zidovudine-based	88	23.6
Abacavir-Based	122	46.7
Stavudine-Based	6	2.3
Tenofovir-Based	7	2.7

4.3 Baseline Characteristics of the Caregivers

Most of the caregivers had primary (36.8%) and secondary levels (30.7%) of education. The HIV status of the mother was found to be positive in 50.4% of the cases, although there was a substantial amount of missing information or 'unknown' status. The HIV status of the father was unknown in 82.7% of the cases. Table 5 illustrates the caregiver characteristics of the children on follow-up.

Table 5: Caregiver characteristics of the Study Population

Caregiver characteristic		**N**	**%**
Education level	None	49	18.8
	Primary	96	36.8
	Secondary	80	30.7
	Post-secondary	3	1.1
Relationship of Primary caregiver to the child	Mother	134	51.3
	Father	22	8.4
	Aunt	36	13.8
	Grandmother	51	19.5
	Other (Uncle, grandfather, elder sibling)	14	5.3
HIV status of mother	Positive	131	50.4
	Negative	3	1.2
	Unknown	126	48.5
HIV status of father	Positive	30	11.5
	Negative	15	5.8
	Unknown	215	82.7
Caregiver source of income	Formal employment	6	2.6
	Informal employment	213	91.5
	Business	3	1.1

4.4 Clinical Characteristics during Follow- up

We recorded the clinical characteristics of the children on their last documented visit before loss to follow-up, or the last visit for those continuing with care. The median CD4 count was 647 cells/ul (Interquartile range 375.0-1029). There was history of treatment for pulmonary TB in 51 (19.5%) of the children, while 49 (18.8%) had ever been hospitalized at least once. Table 6 below shows the follow-up clinical characteristics of the children.

Table 6: Clinical characteristics of the entire cohort of enrolled children at last follow-up

Clinical characteristic	**All enrolled children (n, %) or (median,IQR)**
Age at last visit	11 (8- 14)
Weight at last visit 0 to -1 <-1 to -2 <-2 to -3 <-3	 129 (49.4) 101 (38.7) 31(19.3) 0
Child ever hospitalized? Yes No Information missing	 49 (18.8) 204 (78.2) 8 (3.1)
History of ART regimen switch Yes No	 46 (17.6) 215 (82.4)
Reason for regimen switch Adverse drug reaction Drug interactions Treatment failure No documented reason given	 11 (23.9) 19 (41.3) 4 (8.7) 12 (26.1)
Treated for Pulmonary TB Yes No Information missing	 51 (19.5) 203 (77.8) 7 (2.7)

4.5 Child Retention Status at Time of Study (per Medical record Abstraction)

We categorized status of follow-up as; those in active care, dead, transferred out, or loss to follow-up. Over the study period, 65.5% (171) of the children continued under active care, while 17.2% (45) satisfied the criteria of loss to follow-up. The total follow up time was 1003.9 child years with an incidence rate of LTFU at 44.9 per 1000 child years. More children were LTFU during the first 6 months after enrolment (35.5%).

The table (table 7) and bar chart (Figure 2) below illustrates the status of follow-up.

Table 7: Child Retention Status at Time of Study (Per Medical Record Abstraction)

Characteristic	**Frequency or Median**	**(%) IQR**
Retention Status		
Active	171	(65.5)
Transferred out	32	(12.3)
Dead	13	(5)
LTFU	45	(12.3)
Duration in care in months		
Active	48	24-60
Transferred out	29	18-36
Dead	30	27-34
LTFU	8	4-34
Among LTFU- Time to LTFU	N= 45	
<6 months	16	(35.5)
6 months-1 year	9	(20)
1- 3 years	12	(26.7)
>3 yrs	8	(17.8)
Incidence of Loss to Follow up	44.5 per 1000 child years	

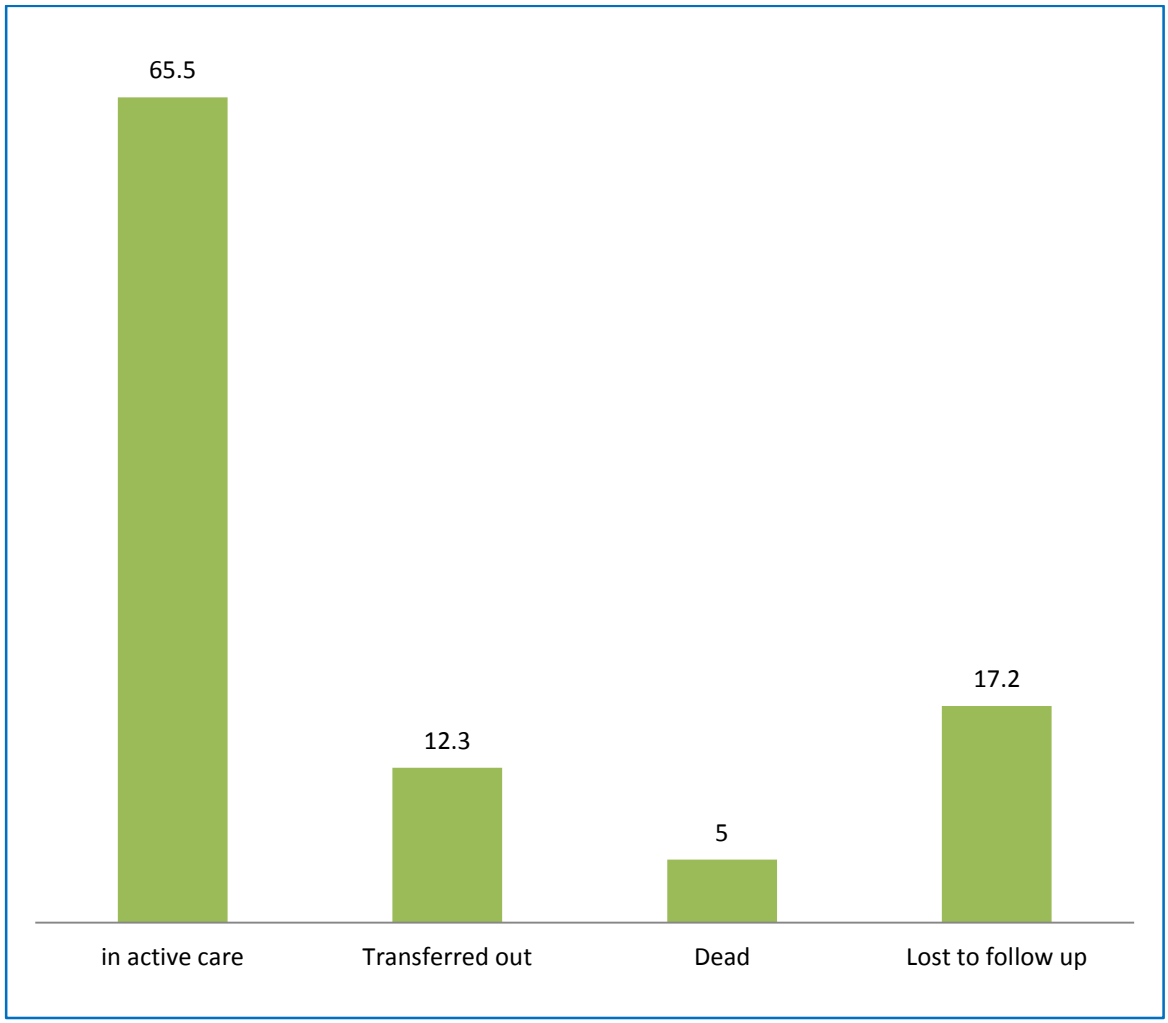

Figure 2: Status of follow-up of HIV-infected children at last available contact at Kangundo Level 4 Hospital.

During the study period Children dropped out of care due to: 13 deaths (5%), 32 transfer outs (12.3%), and loss to follow up (45, 17.2%). The survival curve below shows retention in care among the children on follow up (figure 3).

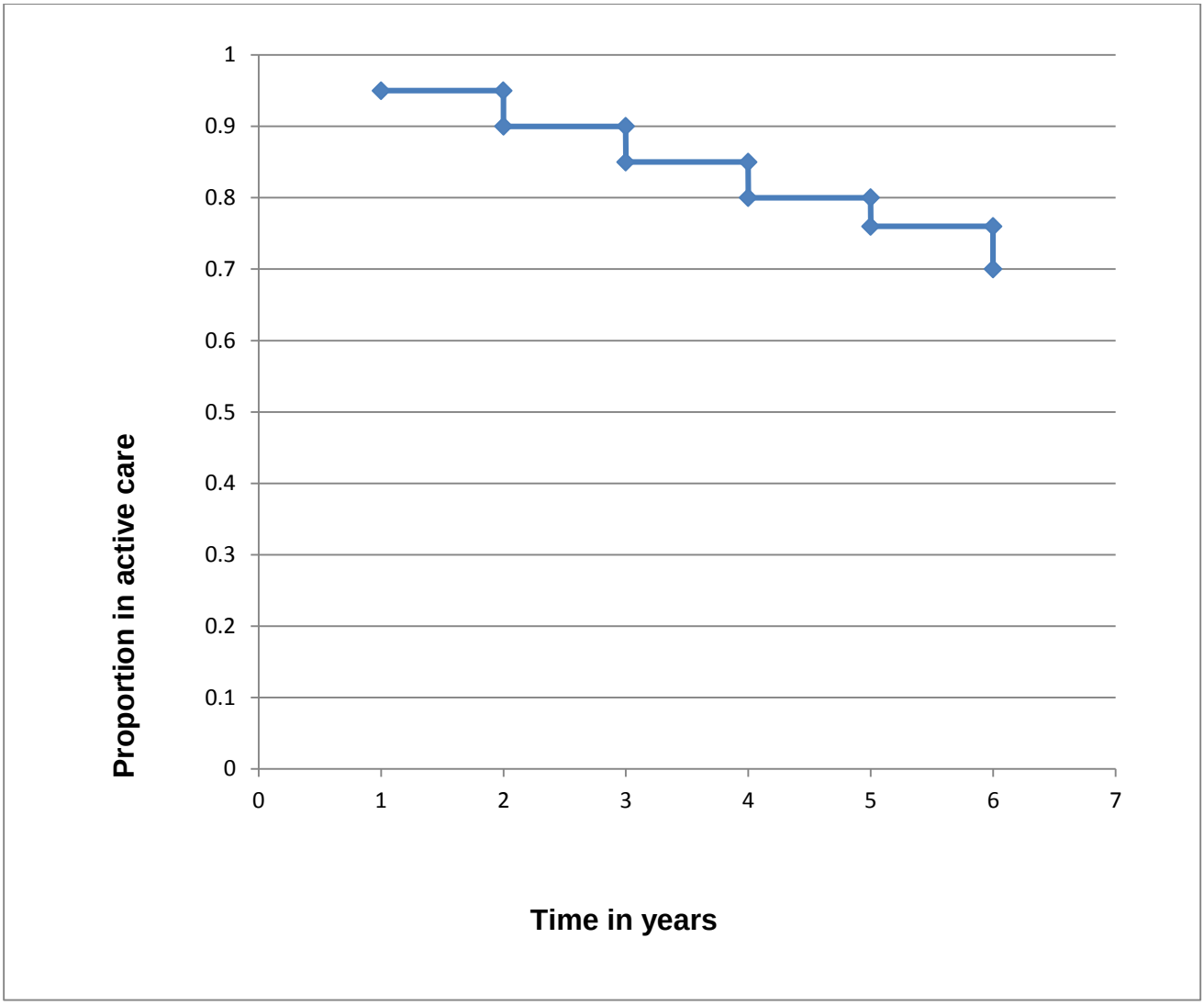

Figure 3: Survival curves showing retention in care among 261 HIV positive children at Kangundo Level 4 Hospital. The time variable reflects time from enrolment to last contact with clinic or last visit.

The flow chart below (figure 4) gives a summary of status of follow up before physical tracing was done.

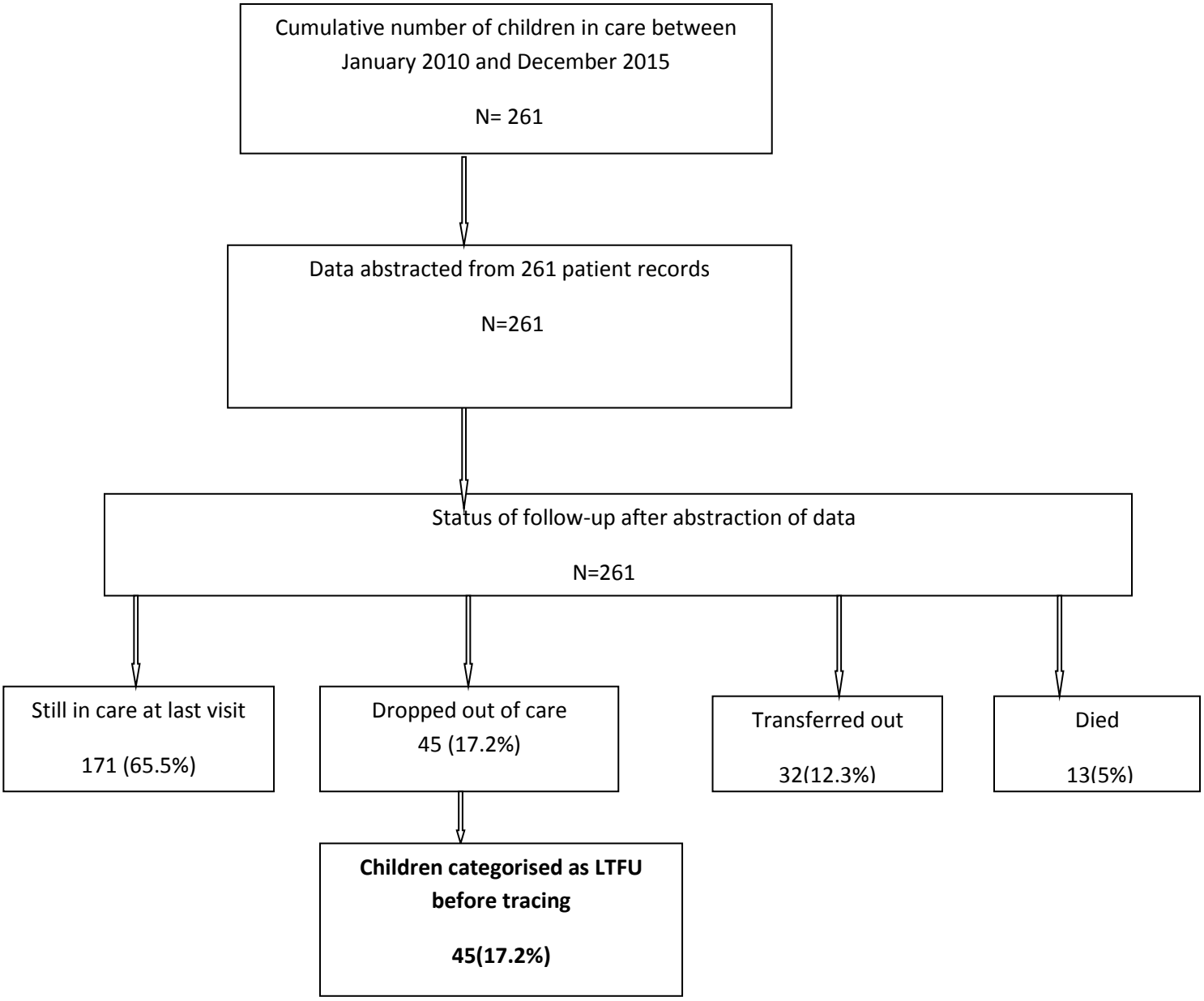

Figure 4: Flow chart showing outcome of follow up at last available medical record

4.6 Predictors of Loss to Follow-up

We employed a univariate analysis to identify potential factors predictive of LTFU. Male children (p= 0.025), children whose caregivers had low level of education (p= 0.001), and child not on ART (p= 0.0001) were among the factors found to be significantly correlated with LTFU. Below is a tabular demonstration the factors associated with loss to follow up (Table 8).

Table 8 Univariate analysis of the factors associated with Loss to follow up

Characteristic	Lost to Follow-up		Not Lost to Follow-up		Unadjusted OR (95% CI) and P-value
	Freq	(%)	Freq	(%)	
Gender					
Male	26	(17.5)	123	(82.5)	1.4 (1.1-1.7), 0.03
Female	19	(16.8)	93	83.2	
Caregiver level of education					
None &Primary	34	(23.4)	111	(76.6)	2.50 (1.05-4.55), 0.01
Secondary &above	11	(13.3)	72	(86.7)	
WHO stage at enrolment					
Stage I and II	36	(18.8)	156	(81.2)	1.88 (0.71-3.22), 0.03
Stage III and IV	7	(9.7)	65	(90.3)	
Primary caregiver					
Parents	28	(17.9)	128	(82.1)	1.12 (1.08-3.33), 0.05
Relatives	17	(16.1)	88	(83.9)	
Caregiver source of income					
Informal employment/farmer	42	(19.5)	183	(80.5)	1.66 (1.182-1.912), 0.039
Formal employment	1	(12.5)	7	(42.5)	
Child on ART					
Yes		(10.4)	198	(89.6)	
No		(57.5)	14	(42.5)	5.83. (4.23-9.76), 0.01
History of regimen switch					
Yes	3	(6.5)	43	(93.5)	
No	38	(18.4)	168	(81.6)	1.4 (1.0-1.6), 0.05

After univariate analysis of the factors most predictive of loss to follow-up, we included those factors whose p value was less than 0.03 in a multivariate logistical regression

model to adjust for each factor and identify the strength of association between each factor and LTFU. We found that low caregiver level of education was most predictive of LTFU (p= 0.001). We chose a cut- off p-value of 0.03 because it was more likely to be predictive of LTFU. Table 9 illustrates the logistical regression model for the selected independent factors associated with LTFU

Table 9: Multivariate model of factors predictive of loss to follow up

Independent variable	Adjusted OR (95% CI)	P- Value
Male gender	1.22 (1.08-2.63)	0.02
Low caregiver education level	2.30 (1.87-3.94)	0.001
WHO Stage I & II	1.62 (1.44-2.09)	0.05
Child not on ART	4.70 (4.43-5.97)	0.03

Logistic regression

4.7 Cross Sectional Tracing of Children who had Dropped out of Care

4.71 Caregiver characteristics of children LTFU who were traced successfully

Out of the 45 children who met the criteria for LTFU, 44 caregivers were successfully traced. The mean age of the caregivers was 48.5 years, with 29 (87.9%) of them being females. The mean approximate distance from home to Kangundo Level 4 Hospital was 11.8km. Grandmothers were the most likely primary caregivers of the children LTFU, as shown in figure 5.

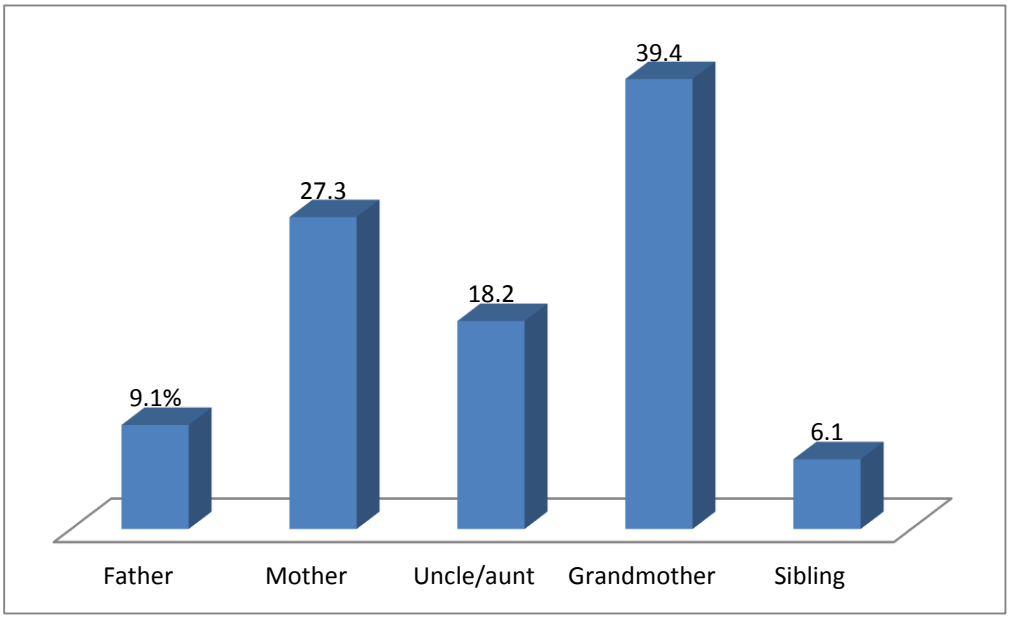

Figure 5: Primary caregiver of children LTFU who were successfully traced

Most caregivers had primary education or below (60.6%, 20) compared to secondary education and above (39.4%, 13). The caregivers were widowed in 42.4% (14) of the

cases, married or cohabiting in 37.5% (12) cases and divorced or separated in 15.2% (5) of the cases.

Predominantly, most caregivers were in informal employment, or casual labour, and seemed to have difficult living conditions. The table 10 below shows the economic characteristics of the caregivers.

Table 10: Economic characteristics of caregivers of children LTFU who were successfully traced

Characteristic		**n**	**%**
Caregiver economic activity			
	Formal employment	1	3.0
	Informal employment	24	72.7
	No answer	8	24.2
How often did you lack food in the past month			
	Never	9	27.2
	Sometimes	19	57.6
	Often	5	15.2
Does your home have adequate drinking water			
	Yes	10	30.3
	No	22	66.7
	No answer	1	3.0
Does your home have a flush toilet			
	Yes	2	6.1
	No	30	90.9
	No answer	1	30
Does your home have electricity			
	Yes	11	33.3
	No	22	66.6
Does your home have a television set			
	Yes	8	24.2
	No	24	72.7
	No answer	1	3.0

4.72 Outcome of follow up for patients whose caregivers were traced successfully

Out of the 45 children who were lost to follow up, we were able to trace and know the status of 44 of them. 33 (75.0%) of the 44 had dropped out of care (True loss to follow up), while 6 (13.6%) were dead, and 5 (11.4%) had transferred to other facilities without referral. The true period prevalence of LTFU over the study period was found to be 12.6% (n= 261). The true Incidence of Loss to Follow- up was 32.9 per 1000 child years.

Among those who self-transferred to other facilities, one went to Machakos because of stigma, one went to Athi river clinic where the father attends clinic, one went to Isiolo (father's place of work), one transferred to a satellite clinic of Kangundo Level 4 Hospital called Kivaani Health Centre, and one to Mbagathi Hospital Nairobi where the mother works. All the children transferred out were reported to be on care and treatment.

We found that the six deaths resulted from opportunistic infections like pulmonary tuberculosis, chronic diarrhea and pneumonia. We were unable to ascertain the cause of death in one of the children. The flow chart on the next page summarizes the outcome of follow-up after physical tracing (figure 6)

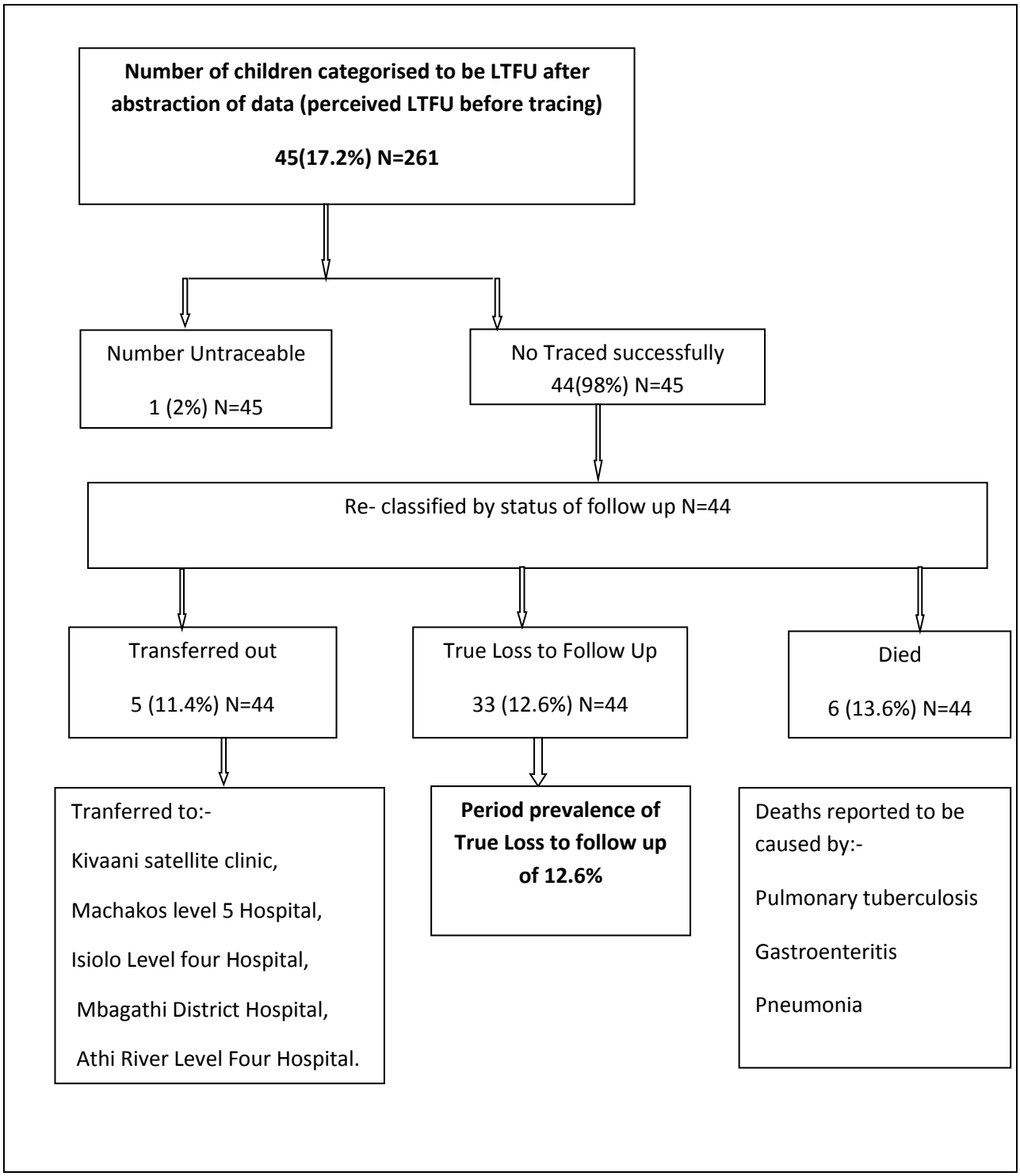

Figure 6: Flow chart showing final outcome of follow up after physical tracing

4.8 Reasons for loss to follow up given by the caregivers who were traced successfully (Questionnaire interview)

The caregivers whose children were successfully traced were asked for reasons for LTFU using an open ended questionnaire. Among the reasons was the parents were also HIV-infected, and had defaulted from care, leaving children with no one to bring them to the clinic. Lack of money to cater for fare was cited as a common reason. Other caregivers said that the child looked healthy and they thought he was cured. One caregiver cited fear of disclosure; he feared that with continued clinic attendance, the child would enquire about the diagnosis, which he was not ready to explain. In another case, the single parent (mother) died, leaving the child under care of an aunt, who was not aware of the HIV status of the child. In some cases, mothers had left children under care of grandmothers, and had not issued any instructions for the child to be brought to the clinic.

Stigma was cited as a major reason; parents were afraid of meeting people who knew them in the clinic. Some caregivers said that their adolescent children refused clinic attendance, saying that they already had enough medication. One caregiver, a father, was deaf and dumb, hence could not hear or understand the instructions for clinic attendance. The reasons for loss to follow up given by the caregivers are summarized in table 11 below.

Table 11 Reasons for loss to follow up given by the caregivers who were traced successfully (Questionnaire interview)

Reason for Loss to follow up	Frequency (%) N=44
Lack of transport to the clinic	33 (75)
Belief that the child looked healthy and was cured	11 (25)
Fear of disclosure	24 (54)
Some caregivers did not know HIV status of the children after parents died	9 (20)
Stigma	27 (61)
Adolescents who would leave home to go to the clinic but do not reach the clinic	1 (2)

4.9 Focus Discussion Group of the Health Care Workers

Focus Discussion Group of the health care workers of Kangundo Level Four Hospital was done. The FDG was conducted in two sessions with 7 and 6 participants respectively. The first session comprised of 7 peer educators of whom 3 were males and 4 were females. All were aged between 40 to 60 years. The second session comprised of 4 female nurses, one male clinical officer, one female pharmacist and one male medical officer. The nurses were aged between 45 and 60 years. The other clinicians were in their early thirties. Each session was conducted over duration of 60 to 90 minutes. The sessions were conducted on 21st and 22nd of December 2015.

After transcribing and summarizing of the data, the following were the main results.

First Theme: Socio- economic factors affecting Loss to follow up

Stigma was cited by the health care workers as one of the main reasons why children became lost to follow up. Children from broken homes were more likely to be loss to follow up than those from stable families. Further more children whose caregivers were of low socio economic status were prone to loss to follow up because they could not afford transport to the hospital.

Session 1, participant 5: "When parents come to clinic and meet with neighbours or relatives who know them, they stop clinic".

Session 2, participant 2: "Those children in boarding schools stop attending clinic or taking drugs because they do not want their friends to know they are HIV infected".

Session 1, participant 1- "Divorced parents interfere with child's follow up. We have seen separation of parents leading to loss to follow up because one parent may go with the children to another location and discontinue care. Sometimes they lack transport".

Second theme: Health system factors associated with Loss to follow up

The health system of Kangundo level four hospital was noted to have an impact on loss to follow up. Some of the factors that contributed to increased loss to follow up included, long waiting time, poor attitude of health care workers, inadequate financial support for tracing of those lost to follow up and poor or inadequate staffing of the clinic. The HIV clinic is located in an open place and this discouraged parents as they felt more exposed to be seen by everyone.

Use of incentives especially snacks for the children improved retention in care.

Session 1, participant 4: "The Hiv clinic is too open and on the way, patients fear being seen by relatives or neighbours".

Session 1, participant 2: "Sometimes patients are so many and they have to wait for so long. It is even worse if they have to go to the laboratory for several tests. They get discouraged and they disappear from clinic".

Session 2, participant 3: "Language used by some of the health care workers at times annoys the guardians who decide never to come back".

Session 2, participant 6: "Defaulter tracing programme stopped funding for physical tracing in the year 2010 and since then we are losing many patients from the clinic".

Session1, participant 2:

"The long waiting line during clinics can be very discouraging. Because we are very few, we keep them waiting and some are totally impatient and just leave. When we try to call them on phone, they ignore our calls. Some never come back".

Session 2, participant 5: "The snacks given to the children in the clinic have changed over time…(appears sad)..initially they used to get milk, bananas, eggs and porridge and they remained in care. Nowadays they only get porridge and are discouraged".

Chapter 5

DISCUSSION

A total of 282 children were followed up during the study period, with 21 excluded from the study because they did not have clearly documented HIV diagnosis. The median age was 10 years, with 57.1% and 42.9% being male and female children respectively.

The child's primary caregiver was the mother in 51.3% of the cases, followed by grandmother in 19.5% of cases. In 41.8% of the cases studied, the biological mother was deceased, while the father was deceased in 48.7% of the cases. This means that a substantial number of the children are under the care of grandmothers and relatives, who often have poor socioeconomic and education status, fuelling loss to follow-up. This has been identified as one of the challenges in the provision of HIV care in resource-limited setting [21].

Overall, caregivers had primary education or no education in 55.6% of the cases, and secondary education and above in 31.8%. In Machakos county, 15% of the residents have no formal education, 58% have primary education, while 27% have secondary education[37]. Our findings among the caregivers of the children under HIV care at Kangundo Level 4 Hospital therefore appear to correspond to the general education status of the entire population of this area. The HIV status of the mother was positive in 131 cases (50.4%) and 'unknown' in 126 cases (48.5). It is expected that nearly all children on follow up acquired HIV through vertical transmission, hence the mothers would be positive in virtually all cases. The high prevalence of unknown status of mothers in this case might sbe explained by two reasons. One, the biological mothers of most children were deceased in 41.8% of the cases, leaving the children under care of relatives, who may not know the HIV status of the mother. This has been reported in another study by Braitsten et al[35] in Western Kenya, where relatives were unaware of the HIV status of the child and the deceased mother. Secondly, non-disclosure by the mother, particularly due to fear of mother-child pair discrimination, violence or even expulsion, might explain why maternal HIV status is not known in many cases. This has been found in other Kenyan studies, and fuels stigma and loss to follow up [6].

The HIV status of the father was positive in 11.5% of the cases, and unknown or not disclosed in 82.7% of the cases. This implies low involvement of fathers during antenatal testing and subsequent care of their children. This has been identified as a big challenge in provision of proper HIV care to children and mothers. In previous studies, the rates of couple counseling with involvement of the male partner are low. In Kenya, a study by John et al[38] found a male attendance of 11% in the antenatal clinics. A rate of 16% was reported by Katz et al[39] and 15% by Farquhar et al[40]. Low male involvement is a predictor of loss to follow up by women and infants in HIV care centres [41]. Paternal contributions to maternal and infant well being and family development are well established[46].

5.1 Magnitude of Loss to follow up

Our study found a true cumulative incidence of 32.9 per 1000 child years of LTFU over the study period and the periodic prevalence to be 12.6%. This rate (magnitude) of LTFU of 12.6% is in agreement with findings from previous studies conducted in Sub-Saharan Africa and other developing countries. Overall, about 21% of patients in HIV programmes are LTFU in Africa[10]. LTFU differs radically across populations because authors use different definitions. For instance, a Ugandan study reported 50.1% of children were LTFU[24], while a South African study reported a LTFU rate of 50.2%[25]. Different definitions of LTFU carry the inherent risk of misclassification of active patients as LTFU. Some studies cite absence of 1 week from a scheduled appointment [14], absence of 2 weeks after an appointment date[12] ,while other use 6 weeks of missed appointment[13]. We employed the WHO definition of LTFU as more than 90 days absence from the missed clinical or drug pick-up appointment without any follow up visit [16], a definition also used by NASCOP, Kenya.

In Kenya, previous studies have focused on HIV programmes in referral hospitals or urban centres. Our study is among the very few looking at LTFU in rural settings. In a study conducted in Western Kenya by researchers from the Academic Model Providing Access to Healthcare (AMPATH) model, 14.2% of children were LTFU. For children

already initiated on ART, 14.1% dropped out of care[8]. This shows that the magnitude of LTFU in this referral setting does not significantly differ from our study in a rural setting. It has been reported that 10-14% of children on ART get lost to follow up in HIV care programmes in Africa[8].

We found that 35.5% of the children lost to follow up dropped out within the first 6 months after enrolment, while 55% dropped out within one year of follow up. Our findings are in concordance with previous authors, who have reported early LTFU within 6 months after enrolment[43]. A meta-analysis of studies from resource-limited settings found that on average, 21% of patients in HIV programmes are lost to follow up within the first 6 months after starting ART[10]. Teasdale et al [29] reported that 29.3% of children in a Mozambican cohort were LTFU six months after enrolment. The KIDS-ART LINC collaboration[30] reported a trend of increasing LTFU over time, in an analysis of 16 paediatric HIV care programmes in lower income African countries. The risk of LTFU was 2.8% at 6 months, 4.6% at 1 year, and 8.4% at 2 years[30].

Some of the reasons for this early LTFU may be that the patients have advanced disease and die shortly after initiation of ART[44]. Others transfer themselves to other facilities shortly after diagnosis is made, mainly due to stigma. There is also a high possibility of denial of status by caregivers of these children during the first few months after diagnosis is made, fuelling the early drop out from care.

5.2 Factors associated with Loss to Follow up

We found that male children were more likely to be lost to follow up compared to female children. Our finding is similar to what has been reported by researchers in South Africa[31], Uganda[32] and the KIDS-ART-LINC collaboration study (2008)[30]. Another study done in Uganda reported a higher incidence of LTFU among female children compared to male, although the difference was not statistically significant[33]. The reasons for the gender difference in LTFU have not been elucidated in the literature, and may vary across ethnicities. This gender difference in LTFU might be attributed to better care of girls by the caregivers. This finding has potential utility in the type of messages given to

the children and their caregivers during adherence counseling. There is need to identify issues facing each of the genders, and address them specifically.

Low caregiver level of education (primary education and below) was associated with increased LTFU. A similar trend has been reported in a Brazilian study conducted in Pernambuco.[21] In the current study setting, most of the caregivers were grandmothers, as the children were orphaned. These caregivers therefore had little or no formal education, and are unlikely to understand the importance of adherence to clinic appointments, and the grave consequences of LTFU. Further, caregivers without formal education are more likely to believe in faith healing and use of traditional medicine, increasing the likelihood of LTFU[35].

Our study found that 67.4% of the children LTFU were in WHO stages I and II. Further, WHO stage I and II was positively correlated with LTFU, with children in this stage 1.88 times more likely to be LTFU compared with those in stage III and IV. These findings are supported by a study conducted in Mozambique[29]. This may be explained by the fact that caregivers have the notion that children with early HIV disease are not sick, and therefore don't adhere to clinic appointments. However, several studies have attributed LTFU to severe immunosuppression. In the KIDS-ART-LINC study[30], there was a positive correlation between LTFU and severe clinical status defined as WHO stages III and IV. Massavon et al[33] found that children in stage III and IV were more likely to be LTFU. Our study also found a significant association between children who had no history of regimen switch and LTFU. This buttresses the previous assertion that children with early disease, whose caregivers think are not sick, are more likely to be LTFU.

Surprisingly, children who had biological parents as caregivers were found to be more likely to be LTFU. A similar trend was reported in the study, wamepotea in Western Kenya, where orphans were less likely to be LTFU[8]. Many studies have also reported that in cases where the biological mother is the primary caregiver, there is a high likelihood of LTFU[31, 32]. A possible explanation is that in most cases, the mother is HIV positive and may be in denial, too ill to honor clinic appointments, or suffering from guilt

(because she is the one who infected the child through vertical transmission). Other studies have disparate results. For example, Kipp et al[45] found that children whose primary caregivers are relatives are more likely to be LTFU. This is because these children are forced to change homes and caretakers, hence difficulties in follow up.

Children whose caregivers were in informal employment were found be more likely to be LTFU in the current study. This may be related to the financial constraints of paying for transport from home, as has been found in previous studies[3]. A study done in Western Kenya found that provision of food to child in the HIV clinic appeared to reduce the incidence of LTFU[46]. This is because most of the caregivers of these children have difficulties providing food and basic amenities to these children, partly because of the cost of other opportunistic infections the child may have.

We found that children not on ART were more likely to be LTFU. This is in agreement with the findings from other studies that have shown that LTFU in the pre-ART group is significantly higher than post-ART initiation group[28]. In our cohort, majority of children were LTFU in the immediate period before 6 months after enrolment. It is possible that before initiation of ART, children and caregivers are not counseled properly, hence are more likely to be LTFU. Those children being started on ART are counseled thoroughly hence are more likely to adhere to clinic appointments. The relationship between ART and LTFU needs further evaluation, because the sample size involved in this analysis was small, hence a diminished statistical power.

For the children LTFU, 44 caregivers were successfully traced. The mean age of the caregivers was 48.5 years and 87.9% of these caregivers were females, especially mothers and grandmothers. They were mainly of low socioeconomic status. This sheds light on low male involvement in care of HIV-infected children in our population[47]. Out of the 44 children traced, 33 (71.1%) were reclassified as true LTFU, 13.3% were deceased, while 13.3% had transferred to other facilities. This mirrors the findings of the wamepotea study in Western Kenya, where 16% of the traced children were found to be deceased[33]. In this study, 11% were found to have transferred to other clinics. The finding that some children initially classified as LTFU may be deceased means that the

mortality rate due to HIV may be higher than thought. A study in Malawi found that HIV patients LTFU had generally higher mortality rate than the general population[48]. This underscores the need for active tracing of these children.

5.3 Health system factors associated with loss to follow up

We found that long waiting time at the clinic contributed to LTFU, as some children and guardians grew impatient after being kept waiting, and decided to drop out of care. In some instances, poor attitude of healthcare workers at the HIV clinic contributed to LTFU. These health system related factors have been reported in previous studies. Some studies found that long waiting periods, disrespectful treatment by health staff and uncoordinated referrals between different HIV services increase the likelihood of LTFU[49-50]. Other factors that contribute to LTFU include stigma. In our study, the HIV clinic is located in an open place, where all entrants into the hospital can see who is attending the clinic. This was mentioned in our FDG as a significant cause of stigma and LTFU. Jones *et al*[49], in a qualitative study, reported stigma and discrimination as important contributors of LTFU.

Use of incentives like snacks for children has been reported to improve retention in pediatric HIV clinics[36]. Our study supported these findings as use of snacks was reported by the health care workers to reduce LTFU in children attending the clinic. Addition of such ancillary interventions in the HIV program may improve the general health of the patients[36].

5.4. Study strengths

- In this study, children lost to follow up were physically traced establishing reasons for LTFU unlike most of the previous studies done on LTFU.
- Use of qualitative approach gave added insight on factors associated with loss to follow up.
- We obtained insight from both the caregivers and health care workers.
- This is the first study on loss to follow up among HIV infected children in rural Kenya.

5.5. Study limitations

- We relied on stored data that lacked some information because it was not collected expressly for the study.
- We only considered the last clinic visit when defining LTFU, hence potentially missing those who fulfilled the criteria for LTFU at some point during their follow up but resumed care.
- Being a single centre study means it is not generalizable to the rural population in the entire country, as ethnic and population differences may exist.

CONCLUSIONS

There was considerable LTFU of 17.2% with an incidence of 44.5 ((95% CI 43 to 47) per 1000 child years among HIV infected children in care at Kangundo Level Four Hospital over the preceding 6 years with most dropping out of care within the first 6 months.

Active tracing gives important insight revealing that 5% are dead or transferred to other HIV clinics and 12% have truly dropped out of care, with a true incidence of LTFU as 32.9 ((95% CI 30.9 to 34.9) per 1000 child years.

Physical tracing of those lost to follow up was successful with 98% of the children lost to follow up traced.

Poverty and lack of transport was cited by most caregivers as major reasons for loss to follow up.

Children from lower socio-economic status families whose caregivers are of low education, male children, those who have early HIV disease at entry of care and not on ART are more likely to drop out of care.

The health care factors associated with LTFU include poor attitude of staff, inadequate staffing, stigma and inadequate funding to facilitate physical tracing.

RECOMMENDATIONS

Policies on physical tracing need to be put in place at the national level to reduce loss to follow up among HIV infected children.

The HIV clinic should have social assessment system that enables identification of poor families and transport provision for them

The caregivers with low education level should be given more counseling to ensure their understanding of the importance of adhering to clinic appointments.

Continuous training of staff in the HIV clinic to improve on knowledge and attitude in care of HIV infected children.

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APPENDICES

APPENDIX I: INFORMED CONSENT FORM (ENGLISH VERSION)

Study Title: THE INCIDENCE AND THE FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AMONG CHILDREN ATTENDING HIV CLINIC AT KANGUNDO LEVEL FOUR HOSPITAL

Study number:

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Introduction

Prevalence of HIV infection is still high among children. With the introduction of ART and prophylaxis against opportunistic infections, these children are able to lead healthy and productive lives. For these interventions to work effectively, measures to prevent loss to follow up need to be put in place.

Purpose and Benefits

Researchers from the University of Nairobi are conducting research on those children

on follow-up in the HIV clinic who drop out of care or are lost to follow up.

This study aims at learning the reasons for LTFU, and the factors that may predict LTFU among children on follow-up. It is being conducted among all children being followed up at Kangundo Level 4 Hospital. No child will be interviewed. Your taking the survey will help us to learn more about the issue of LTFU,

so as to help institute proper policy to minimize and eventually eradicate drop-out from care.

Safeguarding Privacy

The interviewer will keep all information about you secure. Your name will be removed from all records involved in the study. A number will be assigned to the survey questionnaire instead. Only project staff will have access to the study data. We will not use your name when we report results of the survey.

Risks and Benefits

There are no known risks to you as a person taking this survey. There are no known direct benefits to you. However, the overall impact for your community may be great because new data on LTFU will help institute better care and follow-up of children with HIV. We will use this data to determine the factors associated with LTFU among children in rural areas.

Problems or questions

If you have any questions about this research or about the use of the results , you can contact the principal investigator, Dr Winnie Mueni Saumu by calling 254-723-317632.

If you have any questions on your rights as a research participant you can contact Professor

Chindia M.L, secretary, KNH/UoN- ERC by calling Tel. 2726300, ext. 44102, Nairobi.

Respondent Agreement

The LTFU Study has been explained to me. I consent to participate. I have had a chance for my questions to be answered. I know that I may refuse to participate or to stop the interview at any time without any loss of health care benefits that I am

otherwise receiving. I understand that if I have questions about this survey or my rights in taking it, I may contact Dr Winnie Mueni Saumu on 0723317632 or Professor Chindia M.L,Secretary, KNH/UoN- ERC, Tel. 2726300,ext. 44102, Nairobi. Further, I understand that only some information from my child's records will be used in the questionnaire.

Respondent Signature_____ Date_____

Interviewer Signature_____ Date_____

APPENDIX II: INFORMED CONSENT FORM (SWAHILI VERSION)

Study Title: KIWANGO NA SABABU YA WATOTO WANAOFUATILIWA KATIKA KLINIKI YA UKIMWI YA HOSPITALI YA KANGUNDO KUPOTEA KLINIKI

Nambari ya utafiti: _____

Mtafiti Mkuu: Dr. Winnie Mueni Saumu MBChB Paediatrics Resident, University of Nairobi
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Kuanzishwa

Maambukizi ya UKIMWI bado yako kwa watoto. Kuwepo kwa madawa ya virusi vya UKIMWI na madawa ya kuzuia magonjwa wakati kinga ya mwili iko chini imefanya watoto hawa waishi maisha ya afya bora. Ndiposa madawa haya yawe na manufaa zaidi, ni muhimu kuhakikisha watoto hawapotei kwa Kliniki zenye wanafuatiliwa.

Umuhimu wa utafiti huu

Watafiti kutoka Chuo Kikuu cha Nairobi wanachunguza watoto wanaofuatiliwa katika Kliniki ya wagonjwa wa virusi vya UKIMWI katika Hospitali ya Kangundo.

Nia ya utafiti huu ni kubaini ni watoto wangapi wamepotea kliniki na sababu zinazowafanya kukosa kwenda kliniki. Utafiti huu utafanywa kwa watoto wote wanaofuatiliwa katika kliniki ya Virusi vya UKIMWI ya Hospitali ya Kangundo. Hakuna mtoto ataulizwa maswali, ni wazazi ama wanaowatunza hawa watoto pekee. Kukubali kwako kujibu maswali kutachangia pakubwa kutusaidia kujua ni kwa nini

watoto wanapotea kliniki. Pia, majibu yako yatatusaidia kutafuta mbinu za kuzuia hawa watoto kupotea ndiposa wapate matibabu vizuri.

Utaratibu wa utafiti

Utafiti utafanyika kutumia data kutoka kwa rekodi za hospitali, dodoso kwa wazazi wa watoto waliopotea Kliniki na pia vikundi vya majadiliano vya wahudumu wa kliniki.

Hiari ya kushiriki na siri ya utafiti

Kushiriki katika utafiti huu ni kwa hiari yako. Ukiamua kutoshiriki hautanyimwa matibabu yoyote unayopokea.

Majibu yote utakayopeana yatawekwa vizuri kwa siri. Majina yako hayataandikwa mahali popote. Tutatumia tu nambari ya utafiti peke yake. Watafiti pekee ndio wataruhusiwa kusoma maoni yako

Madhara na Manufaa ya utafiti huu

Utafiti huu hauna madhara yoyote kwako. Majibu yako yatasaidia jamii kwa jumla kwa sababu tutajua ni sababu gani watoto wanapotea Kniniki na tutafute mbinu za kuwazuia kupotea kliniki wapate matibabu vyema.

Matatizo au maswali:

Ukiwa na maswali yoyote kuhusu utafiti au matumizi ya matokeo unaweza kuwasiliana na mpelelezi mkuu, Daktari Winnie Mueni Saumu kwa kupiga nambari 254-723-317632**.**

Kama una maswali yoyote juu ya haki zako kama mshiriki katika utafiti huu, unaweza kuwasiliana na Professor Chindia M.L, katibu, KNH/UoN- ERC,simu. 2726300 ,Ext. 44102, Nairobi

Kukubali kwa muhojiwa

Nimeelezwa vizuri juu ya utafiti huu na nimeelewa. Nimepata fursa ya kuuliza maswali na kujibiwa. Najua kushiriki katika utafiti huu ni kwa hiari yangu na nikikataa sitanyimwa matibabu yoyote ninayopokea. Ninajua kwamba kama nikona swali lolote ninaweza kuuliza Daktari winnie Mueni Saumu, nambari ya simu 0723-317632, ama Professor Chindia M.L, katibu, KNH/UoN- ERC,simu. 2726300 ,Ext. 44102, Nairobi

Sahihi ya Muhojiwa _____ Tarehe_____

Sahihi ya mtafiti Mkuu _____ Tarehe_____

APPENDIX III: CASE RECORD FORM

STUDY TITLE: THE INCIDENCE AND FACTORS ASSOCIATED WIYH LOSS TO FOLLOW UP AMONG CHILDREN ATTENDING HIV CLINIC AT KANGUNDO LEVEL FOUR HOSPITAL.

STUDY ID NO: ……. DATE…/… /…..

1. DOB: …….. Age in Years ….. Months ……
2. Gender: Male…….. Female ……
3. Caregiver and relationship with the child
    a. Mother
    b. Father
    c. Aunt
    d. Uncle
    e. Grandmother
    f. Grandfather
    g. Elder Sibling
    h. Other, Specify
4. Is biological father alive? Yes…….. No……..
5. Is biological mother alive? Yes……. No……
6. HIV status of the parents
    a. Mother: Positive……. Negative…… Unknown……
    b. Father: Positive……Negative…… Unknown……
7. Caregiver education level: Nil… Pri…. Sec… Post Sec…. Missing… None……
8. Is the child in school: Yes…… No…….
9. If in school, type of school: a. Day school…… b. Boarding school……
10. Type of housing: Stone …… Wood……. Iron sheets…… Mud……

11. No. of rooms in the house ……..

12. Caregivers source of income

    a. Formal employment

    b. Informal employment

    c. Business

    d. Farmer

Other

(specify)……

SECTION 2: ENROLMENT/ BASELINE CLINICAL CHARACTERISTICS OF CHILD

1. Date of enrolment into the clinic …/ …/ …..
2. Baseline CD4 absolute count…….. cells?mm3
3. Baseline CD4 %.....%
4. WHO stage at enrolment: Stage……
5. Exposure to PMTCT: Yes…….. No…….
6. Weight in Kilograms ……. Kgs
7. Date of enrolment into care …/… /…..
8. On ART? Yes…….. No……
9. Date initiated on ART …/…/…….
10. 1st line ART regimen initiated. Tick one that applies

Common regimens

a) AZT/ 3TC /NVP

b) AZT/ 3TC/ EFV

c) AZT/ 3TC/LPV/r

d) ABC/3TC/ NVP

e) ABC/ 3TC/EFV

f) ABC/3TC/LPV/r

g) D4T/3TC/NVP

h) D4T/3TC/EFV

i) D4T/3TC/LPV/r

Less common regimens

a) ABC/3TC/AZT

b) TDF/3TC/EFV

11. Was the patient started on septrin prophylaxis? Yes…… No…….

12. If yes. Date of septrin initiation …/…. /……..

SECTION 3: FOLLOW UP CASE RECORD FORM

1. Last visit CD4 count……Cells/mm3
2. Last visit weight……Kg
3. Has the patient ever been hospitalized? Yes……. No…….
4. If YES, when was the hospitalization?

	Month	Year	Reason for hospitalization (if available)
1st Hospitalisation			
2nd Hospitalisation			
3rd Hospitalisation			
4th Hospitalisation			

5. History of treatment for PTB YES……. NO……
6. History of Regimen switch or substitution since enrolment YES…..NO……
7. If YES, date of regimen switch……
8. If regimen switched or substituted, reasons for the change
   a. Adverse Drug Reactions
   b. Drug interactions
   c. Treatment failure
   d. No data
9. Status of patient follow up
   a. In active care
   c. Dead

b. Transferred out

d. LTFU

10. If LTFU, duration from enrolment to LTFU

a. Less than 6 months

c. 2 years

b. 1 year

d. More than 2 years

APPENDIX IV: QUESTIONNAIRE FOR LTFU PATIENTS WHOSE CAREGIVERS ARE SUCCESSFULLY TRACED AND CONSENTED

STUDY TITLE

THE INCIDENCE AND THE FACTORS ASSOCIATED WIYH LOSS TO FOLLOW UP AMONG CHILDREN ATTENDING HIV CLINIC AT KANGUNDO LEVEL FOUR HOSPITAL

CAREGIVER QUESTIONNAIRE FORM

1. Sex of the respondent? Do not read this question
    - Female
    - Male
2. How old are you? In years…….
3. What is the relationship with the child?
4. What`s the approximate distance from your current residence to Kangundo Hospital? (In kms)
5. What was the last level of schooling that you completed?
    - No formal education
    - Primary incomplete
    - Primary complete

- Secondary/ vocational incomplete
- Secondary/ vocational complete
- Post secondary or more
- Other, please specify…….
- Declined to answer

6. Are you….?
    - Never married
    - Married/ cohabiting
    - Divorced/separated
    - Widowed
    - Declined to answer
7. Why has the child not been attending clinic
    - Transferred to another facility
    - Dead
    - Dropped out of care
8. What kind of work do you do? By that I mean, what kind activities keep you busy during an average day, whether you earn money from them or not. (*Record answer as given*)

9. During the past month, how often have you had problems getting the food you need?

    - Never
    - Sometimes
    - Often
    - Always
    - Declined to answer

10. Does your home have any of the following:

	Yes	No	declined to
▪ Drinking water from a tap?			
▪ Flush toilet?			
▪ Electricity?			
▪ Television?			
▪ Radio?			
▪ Electric or gas kitchen stove?			
▪ Telephone (not including mobile)?			

11. Have you ever been tested for HIV?

    - Yes
    - No
    - Don’t know
    - Declined to answer

12. Are you willing to tell me your HIV status?
    - Yes
    - No
13. What is your HIV status?
    - Positive
    - Negative
    - Indeterminate
14. Where are you currently being followed up?
    - Kangundo level 4 hospital
    - Kangundo hospital satellite clinic
    - Other health facility
    - Not on follow up
15. If child is LTFU, what are the reasons for dropping out of care? (Allow the caregiver to give reasons for LTFU)
    -
    -
    -
    -
    -
16. During the past one month, has the child missed a dose of ART because you did not have enough food?
    - Yes

- No
- Declined to answer

17. How would you rate the health of your child before starting ART? Would you say it was:
    - Excellent
    - Very good
    - Good
    - Fair
    - Poor
18. Have you seen your child experience any side- effects since starting ART?
    - Yes
    - No
    - Don’t know
    - Declined to answer

APPENDIX V: FOCUSED GROUP DISCUSSION FOR THE HEALTH CARE PERSONNEL WORKING IN HIV CLINIC

STUDY TITLE

THE INCIDENCE AND THE FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AMONG CHILDREN ATTENDING HIV CLINIC AT KANGUNDO LEVEL FOUR HOSPITAL

1. What are some of the reasons why children attending clinic are Loss to follow up?

2. What are health system related factors associated with Loss to follow up

3. What do you think can be done at health facility level to reduce LTFU among children attending HIV clinic at Kangundo District Hospital