DETERMINANTS OF ADHERENCE TO SCHEDULED MEDICAL APPOINTMENTS AMONG HIV INFECTED CHILDREN AGED 18 MONTHS TO NINE YEARS RECEIVING CARE AT KENYATTA NATIONAL HOSPITAL, KENYA

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Determinants of adherence to scheduled medical appointment among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya

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A Thesis Submitted in Partial Fulfillment of the Requirements for the award of the Degree of Doctor of Philosophy in Epidemiology of the Jomo Kenyatta University of Agriculture and Technology

DECLARATION

This thesis is my original work and has not been	presented for a degree in any other
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DEDICATION

This thesis is dedicated to my wife Doris Kithiira and My children, Hope Nkatha, Victor Kiriinya and Miles Muriuki for their support, encouragement and understanding throughout the programme.

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ABBREVIATIONS AND A CRONYMS

AIDS Acquired Immune Deficiency Syndrome

ART Antiretroviral Therapy

ARV Antiretroviral

C.I Confident interval

CCC Comprehensive Care Centre

CD4 Cluster of differentiation 4

CDC Centre of Disease Control

FGD Focus group discussion

GOK Government of Kenya

HIV Human Immune Deficiency Virus

HIV/AIDS Human Immunodeficiency Virus/AcquiredImmunodeficiency

Syndrome

JKUA T Jomo Kenyatta University of Agriculture and Technology

KAIS Kenya AIDS Indicator Survey

KDHS Kenya Demographic Health Survey

KNBS Kenya National Bureau of Statistics

KNH Kenyatta National Hospital

LTFU Loss to follow-up

MS Micro Soft

NACC National AIDS Control Council

NASCOP National AIDS and STD Control Programme

PHD Degree of Doctor of Philosophy

PLWHIV People living with HIV

PMTCT Prevention of Mother to Child Transmission test

SPSS Statistical package for Social Science

SSA Sub-Saharan Africa

SSQ Semi-structured questionnaires

UNAIDS United Nations Program on AIDS

UNICEF United nations Children's Fund

UON University of Nairobi

WHO World Health Organization

DEFINITIONS OF TERMINOLOGIES

Adherence of children to scheduled medical

appointment, which was defined as a child not missing

any scheduled medical appointments

HIV care This refers to appointments for drug refills, medical

review, Nutritional counseling, psychosocial support

and diagnostic/laboratory work-up provided to HIV

infected patients

Primary Caregiver Is any individual(s) mother or guardian with

responsibility of taking the child for clinical

appointments in order to maximize the benefit of

adherence to HIV care.

The CD4 count drop The CD4 count drop of at least 50 cells/mm3 from the

baseline measurement among HIV patients on

treatment is generally recognized as a clinically

significant outcome. Fall in CD4 count is an indication

of possible treatment failure (Williams et al., 1999).

ABSTRACT

Adherence to scheduled medical care appointment among human immunodeficiency virus (HIV)-infected children has been found to be associated with positive health outcomes. The objectives of this study was to establish determinants of adherence to scheduled medical appointment among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital (KNH), Kenya. This was a prospective cohort study involving 221 participants who were primary care givers and their HIV infected children. Study conducted from March, 2017 to November, 2018. Each participant was followed for period of 12 months. Data was collected using pretested questionnaire and review of standardized clinical notes on adherence to scheduled medical appointments and determinants of adherence to scheduled medical appointments. Two focus group discussions (FGDs) consisting of 8 purposively sampled primary care givers were undertaken to support the quantitative findings. The analysis of quantitative data was done using Statistical Package for Social Sciences (SPSS) Version 20. Analysis for association between adherence to scheduled medical appointment and determinants factors were done on both univariate and multivariate analysis, Data from focused group discussions was analysis based on themes. Informed consent was obtained and signed by primary care givers of the children voluntary. Confidentiality and privacy was maintained. Ethical approval no P688/09/2016) was obtained. This study found adherence to scheduled HIV medical appointment among study participants to range from 75.6% to 81.9% at 6 and 12 months respectively. The higher the CD4 counts the lower the likelihood of adherence to scheduled medical appointments. At 12 months of follow up there was an increasing trend for higher odds of missing scheduled medical appointments with an increase in CD4 counts aOR 19.32 (95% CI 2.73 - 136.78) CD4 1000 -1499; 21.48 (95% CI 3.64 - 126.62) CD4 >= 1500 when compared to children with < 500CD4 count. Children clinical factors associated with adherence to scheduled medical appointment at 12 months of follow up were; receiving HIV treatment in the scheduled health facilities and having lower CD4 cell counts. Children primary care givers perceived HIV care services as very beneficial to the health of their children. Determinants of adherence to scheduled medical appointments among HIV infected children are low CD4 cell counts, receiving HIV treatment at the scheduled health facilities. Care givers perception on HIV care services provided to their HIV infected children as very beneficial to their health. Children with high CD4 counts should be targeted by Health care providers for individualized intervention to ensure they adhere to all scheduled medical appointments. Ministry of health and HIV policy makers to emphasize that all children to receive HIV treatment in the scheduled health facility by enhancing it in policies that deals with HIV prevention and differentiated care model for people living with HIV.

CHAPTER ONE

INTRODUCTION

1.1 Background Information

Worldwide HIV infected children are left behind by the global HIV / AIDS response. There were approximately 38 million people across the globe with HIV/AIDS in 2019. In 2019, only 53% (950 000) of the 1.8 million children were living with HIV globally were diagnosed and on treatment, compared to 68% of adults (UNAIDS, 2020). Two thirds of the children globally fail to attend medical facilities regularly thus failure to receive benefits of Pediatrics HIV treatment. An estimated 95 000 children died of AIDS related illnesses in 2019. Global partners who are committed to ending paediatric AIDS have come together to call on countries to scale up access to optimal treatment for HIV infected children (UNAIDS, 2020). Studies have found decrease in HIV related child mortality where early care and treatment for children has been initiated and maintained (UNAIDS, 2014). Globally, multiple cohort studies have found out that 25 to 44% of HIV infected children misses attendance of scheduled medical appointments in many developed countries (Brennan et al., 2010). WHO treatment guidelines calling for universal treatment for HIV infected children (Sengayi et al., 2013), attention must be focused at every point that infant and children are lost from care, with a particular emphasis on ensuring proper retention in care of children known to be HIV infected. Among the highest risk groups, and one of the most severely under-studied and under-treated are the children of sub-Saharan Africa (WHO, 2008). Current pediatrics guidelines, all confirmed HIV positive children are put on treatment regardless of their CD4 counts (Makurumidze et al., 2020).

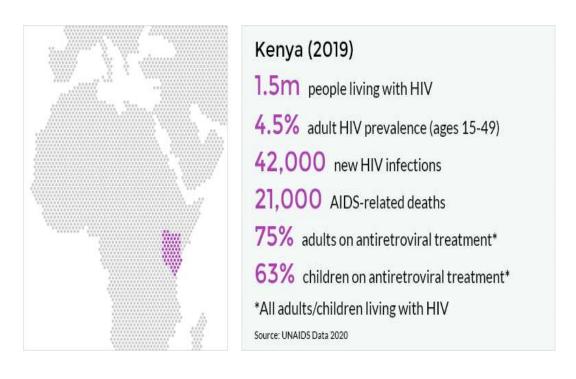


Figure 1.1. HIV Figure 1Data in Kenya

The adherence rate to care among people living with HIV is higher in the first 12 months (about 82%) and reduces to about 61% at month 60 (Braistein et al., 2011). The study done by De Baets et al, (2007) found that the rates of children missing medical appointment are affecting HIV care among children in Kenya. Those children who miss to attend scheduled medical appointment they are at high risk of getting lost to care. In western Kenya, lost to follow up among children has been documented at 18.4 per 100 child-years (Braitstein et al., 2010). As treatment becomes more available and more effective, attention is moving towards prevention, including secondary and tertiary prevention, and to the populations most vulnerable to the ravages of the HIV pandemic. Prospective cohort study done in Kenya among HIV-1 infected children who initiated highly active antiretroviral therapy at advanced immunosuppression it was observed high early mortality. The first 4 months after HAART initiation were associated with highest mortality, and children who survived this period were less likely to die in the subsequent two years of follow up (Wamalwa et al., 2010). Prospective study done in western Kenya that randomly sampled HIV infected and exposed children who became lost to follow up noted varies reasons for these cases. The reasons were HIV disclosure and discrimination, a preference for traditional medicine and faith healing (Braitstein *et al.*, 2011).

Studies have explored factors associated with lost to follow up in children (De Baets et al., 2007). However, few studies have examined this from the perspective of the caregivers responsible for ensuring vulnerable children adherence to attendance of HIV care regularly (Vreeman et al., 2009). Studies are needed on adherence to scheduled medical appointment among other group of people on HIV care (Bigna et al., 2014), HIV treatment and care in children is more complex than in adults. Efforts to maximize the treatment efficacy in children must take account of the children clinical factors and children caregiver(s) factors and perception and the influences of the family and society. Progress has been made in treating HIV-infected children in recent years, especially in developing settings; children have unacceptably high rates of treatment failure and drug resistance (Fox and Rosen 2015). Majority of children in developing settings have little or no access to second line therapy, and children in developed settings are struggling with chronic treatment. Many HIV infected children are living to adolescence and engaging in sexual relationship, which creates a public health risk of HIV transmission (Nijhawan et al., 2016). Adherence to regular medical appointments among the children in HIV program is significant in improving their health outcome (Samuel et al 2015; Mchugh et al 2017); the need to ensure that HIV infected children are retained in regular care is a pressing public health issue and it affects multiple populations. Among the children it is the responsibility of the care giver to ensure their children are adherence to scheduled medical appointment on HIV care and treatment, in order to maximize the benefit of adherence in care and treatment.

Factors associated with adherence of children on HIV care and treatments are; intrapersonal, interpersonal, organizational, community and policy levels factors. The complexity of the interactions of these factors within these levels is critical in defining the adherence of children on HIV care and treatment (Wachira *et al.*, 2012). Missing HIV care appointments leads to higher mortality rates, compared with not missing any appointments (Rosen and Fox, 2011; Mugavero *et al.*, 2009). There is need to add more knowledge on factors associated with adherence to scheduled medical appointment among children on HIV care and treatment to maximize the benefit of paediatric HIV treatment.

1.2 Statement of the problem

HIV in children remains a major public health problem of concern as it leads to increased morbidity and mortality. The adherence of children to scheduled medical appointment for HIV care is critical in maximizing the success of treatment programme. Globally 25% to 44% of HIV positive children miss adherence to scheduled medical appointments, increasing their risk for morbidity and mortality, opportunistic infection and drug resistant. As of 2020 63% of children in Kenya were on HIV treatment compared with 75% of adult were on HIV treatment (NASCOP, 2020). Children are dying of HIV infection due to low CD4 cell counts, High Viral load, having Opportunistic Infection and on Second line treatment at Kenyatta National Hospital. Yet they miss scheduled medical appointments for HIV care and treatment, (KNH appointment register for HIV care, 2016). Adherence to scheduled medical appointments is high among adult as compared to children, while mortality is high among children as compared to adult. Determinants of adherence to scheduled medical appointments; caregiver related factors, Children clinical factors, services provided and perception of primary care are understudied among children aged 18 months to nine years. Studies have focused more on adherence to drugs among children (Brennan et al., 2010). More locally generated data is needed on determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya.

1.3 Justification of the study

Globally 25% to 44% of HIV positive children miss scheduled medical appointment hence decreases chance of receiving benefits of HIV care. (Brennan *et al.*, 2010). Children care outcome defends on adherence to scheduled medical appointment. Thirty seven percent of HIV positive children were not on HIV treatment by 2019 (UNAIDS 2020). Primary caregiver related factors, Children clinical factors, services provided and perception of primary care giver on HIV services provided to their children makes adherence to scheduled medical appointment very challenging. The study finding may be used by policy makers, health care providers to enhance

intervention for adherence of attendance of scheduled medical appointments among HIV infected children leading to achievement of HIV treatment goals hence reduced morbidity and mortality thus individual health and population health.

1.4 Research questions

- 1. What is the adherence level to scheduled medical appointment on HIV care services among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya at six months interval?
- 2. What is the association between CD4 count services provided and adherences to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya at six months and 12 months during study period?
- 3. What are the association between children clinical factors and adherence to scheduled medical appointment among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya?
- 4. What are the care givers perceptions associated with adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya?

1.5 General Objective

To establish determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya

1.5.1 Specific objectives

- 1. To determine the lever of adherence to scheduled medical appointment on HIV care services among HIV infected children aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya at six months interval
- 2. To determine the association between CD4 count, services provided and adherence to scheduled medical appointments among HIV infected children

- aged 18 months to nine years receiving care at Kenyatta National Hospital, Kenya at six months and 12 months during study period.
- To establish the association between children's clinical factors and adherence to scheduled medical appointment among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya.
- 4. To determine care givers perceptions associated with adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya.

1.6 Conceptual Framework

The study framework was built upon the integration of the social ecological model (McLeroy *et al.*,1988) which recognizes that behavior is influenced at multiple levels, including the intrapersonal, interpersonal, organizational, community and policy levels. The complexity of the interactions within these levels is critical in defining the determinants of caregivers ensuring their children adhere to scheduled medical appointment. Specifically, the study will focus on the factors associated with of adherence of HIV infected children on scheduled medical appointments. The association between independent variables: Child Age, gender, CD4 counts, caregiver relationship with the child, care giver: Age, education level, Marital status, HIV status, social economic status (employment: income, transport cost, time constrain, psychosocial support (family support, stigma). Scheduling of appointment, and Relationship with health providers, Perception of care giver on services provided (perceived benefit, perceived problem and dependent variable; Adherence of children to scheduled medical appointments which was defined as a child not missing any scheduled medical appointments.

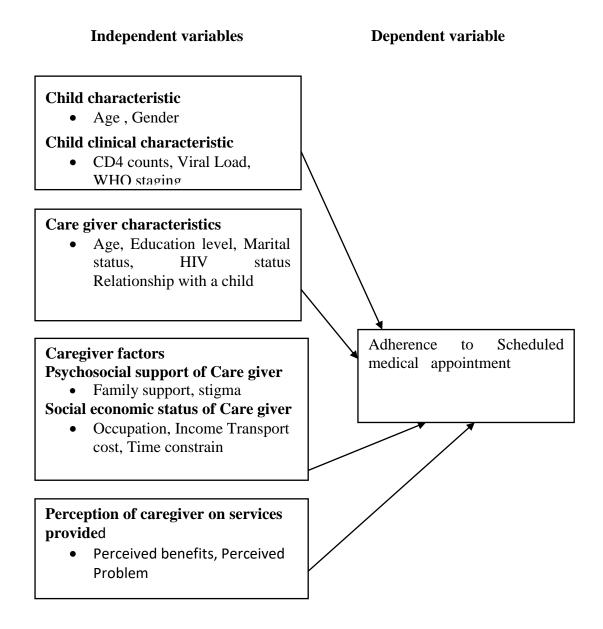


Figure 1.2: Conceptualized relationships among variables

CHAPTER TWO

LITERATURE REVIEW

2.1 HIV/AIDS and adherence to scheduled medical appointments

Human Immuno-deficiency Virus (HIV)-infected patients' retention in care is a necessary condition for maintaining or restoring health and requires adherence to all HIV scheduled medical appointment. Adherence of children to scheduled medical appointments is success of paediatric HIV treatment key (WHO/UNAIDS/UNICEF (2011). There were approximately 38 million people across the globe with HIV/AIDS in 2019. Worldwide children living with HIV continue to be left behind by the global AIDS response. In 2019, only 53% (950 000) of the 1.8 million children living with HIV globally were diagnosed and on treatment, compared to 68% of adults. UNAIDS reports that in 2019, of all people with HIV worldwide: 81% knew their HIV status, 67% were accessing ART, 59% were virally suppressed (UNAIDS, 2020). To improve on these requires individuals to adhere to attendance of HIV clinic among others. Two thirds of the children do not attend health facilities regularly thus failure to receive benefits of Pediatrics HIV treatment. An estimated 95 000 children died of AIDS-related illnesses in 2019, (UNAIDS, 2020). The burden of HIV infection is highest in sub-Saharan Africa. Globally, multiple cohort studies have found out that 25%-44% of HIV infected children misses scheduled medical appointments in many developed countries (Brennan et al., 2010).

There is need of regular contact of infected children with' health care providers at health facility to maximize the benefit of HIV treatment. The children are lost at every step along the continuum of care, particularly in the period between HIV diagnosis and treatment. Poor adherence of children to scheduled medical appointments, is a major driver of poor performance and increased morbidity and mortality in HIV/AIDS programme (Fox and Rosen, 2015). Retention in HIV care is the ability to adhere to critical aspects of care, attend regular follow-up appointments, scheduled lab tests, and other monitoring activities, according to health system standards and as prescribed by a health care provider (Patel *et al.*,

2010). Adherence to scheduled medical appointment is critical to reduce HIV-related morbidity and mortality, reduce the incidence of new infections in children and adults, and reduce development of ART resistance). Keeping HIV-infected patients connected to care should be a major health care and public health priority. Improving patient retention will reduce morbidity, comorbidities, and transmission, ultimately leading to better patient and population health. Missing HIV primary care appointments leads to higher mortality rates, compared with not missing any appointments (Mugavero *et al.*, 2009).

Retention in care has been highlighted as an important element of clinical success for the patient and the program. Attending scheduled medical appointments regularly is associated with favorable patient outcomes among individuals with HIV on ART (Berg et al., 2005). Non adherence to scheduled medical appointment has been found to be associated with higher mortality for children in both high-income and resource-limited settings (Sengayi et al., 2013). A study from Kenya found that patients not retained in care are generally sicker than those who are retained in care and may therefore experience poorer long-term outcomes (Mugavero et al., 2010). In addition to retrieving medication, clinical follow-up visits are crucial for monitoring drug toxicity, clinical HIV progression, and to diagnose and treat new opportunistic infections (OIs) and other concurrent diseases that may occur (Patel et al., 2010). Missing a single scheduled clinical visit is a risk factor to lost-to-follow-up. Although overall treatment adherence among sub-Sahara African children has been high, recent evidence suggests that a large number of infected children in the region who have started treatment programs are poorly retained in HIV care.

2.2 Adherence to scheduled medical appointments among HIV infected Children

Adherence to scheduled medical appointment is defined as a child not missing any scheduled medical appointments (Horstmann, 2010; Mugavero, 2010). The study done in USA on HIV clinic attendance found out that majority of patient attended 76% of their scheduled appointments (Walburn *et al.*, 2012). Study done by Braistein *et al.*, (2011) found that the adherence rate of children on regular HIV clinic

attendance is higher in the first 12 months about 82% and reduces to about 61% at month 60. Adherence to regular medical appointments among the children in HIV program is significant in improving their health outcome (Wachira *et al.*, 2012). Missed medical appointment have been associated with a higher incidence of opportunistic infections, AIDS defining illness, and death among children (Mugavero *et al.*, 2010; Nijhawan *et al.*, 2016). Children who attend HIV clinic regularly have the opportunity to be treated for HIV-related diseases early hence reduced morbidity and mortality (Park *et al.*, (2007). Missed clinic appointment should trigger concern about patients at risk of defaulting on their care (Bastard *et al.*, 2012). Regular clinic attendance for HIV care is important for successful clinical outcomes in HIV treatment (Mugavero *et al.*, 2009). Multiple studies have used missed clinic visits as a measure of retention and are generally applied as either a dichotomous variable (yes/no) (Kunutsor *et al.*, 2010; Magnus *et al.*, 2010) or a count (number of missed visits) (Brennan, 2010).

2.3 CD4 cell counts and adherence to scheduled medical appointments

The CD4 + T-lymphocyte count drop of at least 50 cells/ mm3 from the baseline measurement among HIV patients on treatment is generally recognized as a clinically significant outcome. Fall in CD4 + T-lymphocyte count is an indication of possible treatment failure (Samuels *et al.*, 2015). For HIV-infected patients receiving antiretroviral therapy, routine laboratory monitoring is associated with improved health and survival compared to clinical monitoring alone (Mermin *et al.*, 2011). Regular monitoring of patients with CD4 cell counts has been shown to be cost-effective (Kahn *et al.*, 2011). Studies done by Braintstein *et al.*, (2011), Horstman *et a.*, (2010) that pointed out that children with low CD4 counts is a risk factor of adherence to scheduled medical appointment. Study done by Massavon *et al.*, (2014) found out that children with low CD4 counts are more likely to be severely very ill hence higher chances of being admitted to hospital hence fail to adhere to scheduled medical appointments.

2.4 Care giver factors associated with adherence to scheduled medical appointment among children

Caregivers has the primary responsibility of ensuring their children are adherent to medication and maintain their clinic appointments. Few studies have examined this from the perspective of the caregivers responsible for ensuring their children are retained in HIV care (Vreeman *et al.*, 2009). Studies have found the age of caregiver, marital status and economic status (Ugwu *et al.*, 2013). and lever of education are caregiver demographic factors associated with adherence to scheduled medical appointment. (Wachira *et al.*, 2012), Poor mental health is common in caregivers of HIV-infected children and has been found to influence caregiver support of a child's adherence to attendance of appointments. (Havens & Mellins, 2008). There are many factors influencing caregiver decisions regarding whether children receive treatment or not; these include transport costs, food availability, time constraints, (Wachira *et al.*, 2012).

In one study, 30% of caregivers reported that children failed to attend scheduled medical appointment because caregivers either had not disclosed their own HIV status or were afraid of family/community stigma related to their HIV status or that of the child (Braintstein *et al.*, 2011). The family support members are needed to help to remind the primary caregiver about scheduled medical appointment and facilitating access to HIV care and treatment. The caregivers may be unaware that pediatric HIV treatment is available and thus perceive no benefit in seeking these services for children (Cohen *et al.*, 2010).

Where care givers perceived low level of Stigma and discrimination and good attitudes from healthcare workers they are more likely to adhere to scheduled medical appointments of their HIV infected children (Horwood *et al.*, 2010). The care giver may be reluctance to reveal the status of their children due to fears of stigma and discrimination hence fail to adhere to scheduled medical appointments (*Naar-King et al.*, (2007). Fear of disclosure of HIV status of their children among their family members has been noted as a barrier to engaging in HIV care services (Caroline et al., 2014). Cultures which have strong histories of traditions where

couples support one another, there are more likely to adhere to scheduled medical appointments hence improve the outcome of HIV treatment (French *et al.*, 2017),

2.5 Children clinical factors associated with adherence to scheduled medical appointments among HIV infected children

The level of CD4 Counts among children influence the decision of care giver to adhere to scheduled medical appointment or not (Makurumidze *et al.*, 2020). Attending all clinic appointment is crucial in ensuring uptake of HIV treatment hence achievements of UNAIDS 95:95: 95. (Van der Kop et al., 2018). Study done by Braintstein et al., (2011); pointed out that high CD4 cell counts is a risk factor of missing scheduled medical appointment among children. Studies done by Horstman *et al.*, (2010) have found out that children infected with HIV suffering from opportunistic infection may influence decision of caregiver on adherence to scheduled medical appointment

The children in WHO stage 3 and 4 are likely to be very sick and may contribute to decision of care giver to adhere to scheduled medical appointments. Horstman *et al.*, (2010). The study done by MChugh *et al*, (2017) pointed out that Missing clinic appointment is associated with missing treatment and hence a strong predictor for Virological failure. The health condition of the child may determine whether care giver will take the child to HIV medical clinic or not (MChugh *et al*, (2017).

2.6 Caregivers perception associated with adherence to scheduled medical appointments among HIV infected children

2.6.1 Caregivers perception on benefits of adherence to scheduled medical appointment

Care givers perceive that once the HIV infected children adhere to scheduled medical appointment it increases likelihood of receiving the benefits of HIV treatment; that is improves the health status, reduces morbidity and mortality (Caroline *et al.*,2014). Reduces hospital admission and increases Viral suppression (Nabukeera *et al.*, 2021). Reduces opportunistic infection (Van der kop *et al.*, 2018) Reduce drug resistant

(Bastard, 2012), and delays developing AIDS defining symptoms (Foresto *et al.*, 2017). Create opportunity for health care workers to assess the health status of the HIV infected patient and prevent medication interruptions (MChugh *et al*, 2017)

2.6.2 Perception of Caregivers on factors motivating adherence to scheduled medical appointment

Caregivers perceive the following factors as motivating to adherence to scheduled medical appointment among HIV infected children; HIV care services provided to their HIV infected children Schneiderman *et al.*,(2016), taking short time in the medical clinic (Ezekiel *et al.*, 2012) .Having friendly health care workers and appreciating them (Brainstein etal., 2011) Having opportunity to discuss with Health care workers on the scheduled medical appointments (Massavon *et.al*, 2014).

2.6.3 Caregivers challenges associated with adherence to scheduled medical appointment

Caregivers perception on challenges associated with adhering to scheduled medical appointment s to include poverty, lack of food, distance to the clinic and transport costs have been expressed as barriers to pediatric HIV care (Vreeman et al. 2009). Most caregiver has heavy financial burden which overweighs their income and thus leads to challenges of taking their children to scheduled medical appointments. Caregiver busy work schedule and lack of time influence decision of caregiver on adherence to scheduled appointment (Horstman et al., (2010). Perceived stigma and discrimination continue to pose a major threat to adherence to scheduled medical appointments (Fox and Rosen., 2015). Caregivers interpret high CD4 cell counts to mean improved health and thus influencing decision of care giver to take their children to the scheduled medical appointments (Ezekiel et al., 2012). Perception of caregivers on Health care providers and facility-level challenges influence decision of care giver to adhere to the scheduled medical appointments of their children, There are many perceived challenges that affect children adherence to scheduled medical appointment in HIV care; health care worker shortages, increased workload, and attitudes of health care workers towards patients. Structural barriers within the clinical care setting, scheduling of appointment time interval to the next scheduled

appointment, the longer the time period to the next appointment, the higher the failure rate of adhering to appointments (Kerr *et al.*, 2012; Horwood *et al.*, 2010).

Care givers perception on ways of improving adherence to scheduled medical appointment.

Care givers perceive some of the solutions to promote adherence to scheduled medical appointments include: Reducing the number of scheduled medical appointments Ezekiel *et al.*, (2012) reducing waiting time in the HIV Medical clinic (Van der kop *et al.*, 2018).

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study Site

The study was undertaken at Kenyatta National Hospital, Comprehensive Care Centre (CCC) in Kenya. The Centre provides free comprehensive HIV care services. KNH, which is the biggest referral hospital in East and Central Africa found about two kilometers out of the CBD in Nairobi city, Nairobi County, Kenya. HIV infected children are referred with low CD4 counts, High Viral load, opportunistic infection, On Second line treatment with all forms of complication for specialized treatment. The comprehensive care entails ART, treatment of opportunistic infections, nutrition counseling and supplementation, psychosocial care and laboratory and radiologic tests through funded program by Centre of Disease Control (CDC) and Government of Kenya (GOK). Primary Caregiver has responsibility of taking the child for clinical appointments in order to maximize the benefit of HIV care services. Approximately 350 children aged 18 month to nine years were receiving HIV care services at the center. The KNH CCC acts as the main HIV pediatric training center and therefore the knowledge and skills learned are likely to be applied to lower level facilities.

3.2 Study Design

Prospective cohort study done from March, 2017 to Nov, 2018 .Each participant was followed for 12 months assessing adherence and determinants to scheduled medical appointment.

3.3 Target Population

HIV infected children aged 18 months to nine years.

3.3.1 Study Population

The study population was HIV infected children aged 18 months to nine years receiving HIV treatment.

3.3.2 Inclusion criteria

HIV infected children aged 18 months to nine years receiving HIV treatment at Comprehensive Care Centre, KNH, Kenya and has adhered to scheduled medical appointment for the last six months. Written informed consent was voluntarily provided by their primary care giver,

3.3.3 Exclusion criteria

Children who were severely sick and requiring admission at the time of recruitment. Written informed consent was not provided by their primary care giver. Children who was on transit

3.4 Sampling

3.4.1 Sample size determination

This study used Fisher *et al.*, (1998) formula to calculate sample size as outline below. This study used a conservative prevalence of 50% of adherence to scheduled medical appointment among HIV infected children aged 18months to nine years, since they was no studies that had reported the prevalence of the same study population in the same setting

$$n = [Z^2 p(1-p)/d^2]$$

therefore

Where, **n** is the required minimum sample size,

Z= is a standard score corresponding to 95% CI thus equal to 1.96,

p = 50% proportion of children adherence to scheduled medical appointment.

d= is the precision around the prevalence ($\pm 4\%$)

$$\mathbf{n} = [1.96^{2} * 0.5(1-0.5)/0.04^{2}] = 600$$

The CCC KNH register had approximately 350 children aged 18 months to nine years who were on HIV treatment. Given that this entire population in of 350 is <10,000, the finite population correction factor was applied to determine the final samples size and is outline below:

$$n = \frac{n_0}{1 + \frac{n_0 - 1}{N}} = \frac{600}{1 + \frac{600 - 1}{350}} = 221.2 \text{ Approximately } 221$$

Sample size of 221

3.4.2 Sampling method

Consecutive sampling method was used. In KNH register record had approximately 350 children aged between 18 months and nine years who were on HIV treatment in the beginning of the study. The research aimed to recruit all the study participant who meet the inclusion criteria in every working day until all available participants who qualified to be included in the study were requested to participate and those who accepted were enrolled until we reached the target sample size.

3.5 Data Collection Tools

3.51. Quantitative data collection tools

Semi-structured questionnaires were used to correct data. Two clinician completed standardized data collection forms on WHO staging, CD4 count/ viral load, date of child visit and next appointment return date, which is the routine services provided at KNH, CCC. The follow up of participants (Child/ Primary caregiver) was done for 12 months to assess determinants and adherence of HIV infected children to scheduled medical appointment on HIV care services at baseline, six months and 12 months.

3.5.2 Qualitative data tools

Two focus group discussions (FGDs) was done where purposive sampling was used to select eight participants per group of HIV infected children primary care givers both male and female were undertaken to support the quantitative finding. Focus group discussion guide was used (Appendix II) by principal investigator who created rapport and moderated the session in an open free-flowing discussion at convenient private room. Two trained research assistant used audio tapes and a notebook to collect data on perception of primary care giver on services provided; perceived benefit, perceived problem and ways of improving services related with adherence of children to scheduled medical appointments on HIV care services within 30 to 45 minutes.

3.6 Study Variables

3.6.1 Dependent Variables

Adherence of children to scheduled medical appointment

3.6.2 Independent variables

Demographic characteristics of the caregiver: Age, education level, Marital status, HIV status, social economic status (employment: income, transport cost,) Demographic characteristics of the child: Child Age, gender, Primary caregiver relationship with the child. Clinical characteristics of the child: WHO stage, Viral load, CD4 count, history opportunistic infections, Perception of primary care giver on services provided (perceived benefit, perceived problem). Psychosocial support; family support, stigma, scheduling of appointment and relationship with health care providers.

3.7 Data management and analysis.

Data was cleaned and cross-checked for entry errors and range checks. The quantitative data was analyzed using Statistical Package for Social Sciences (SPSS), version 20.0 for windows. The descriptive statistics were done. Association between

determinants factors and adherence to scheduled medical appointments was explored through logistic regression model. Bi-variate analysis to explore for crude associations between adherence to scheduled medical appointment and the various independents variables was done. Multi-variate analysis was done to identify predictor variables for adherence to scheduled medical appointment was done. Variables that had a p value <0.05 were considered for multivariate analysis. Stepwise forward selection method was used to establish significant predictors of adherence to scheduled medical appointments. A likelihood ratio test was used to identify the multivariable model with factors that best explained adherence to scheduled medical appointments. For the logistic regression crude and adjusted Odds Ratios (OR), 95% Confidence Interval (CI) and associated P value have been reported and P value < 0.05 was considered significant. Data from FGD was analysis based on themes (deductive thematic analysis). The data was entered and stored on a desktop which was protected by use of password while questionnaires and focus group transcripts was kept under lock and key with only authorized study personnel having access.

3.8 Data presentation

The frequencies were used to present categorical variables. Qualitative data were presented in verbatim.

3.9 Ethical considerations

This study ensured restricted access to the information collected and coding of questionnaires were observed. The research was approved by the KNH/UON ERC (approval no P688/09/2016) to collect data from consenting primary care givers. The written informed consent was obtained and signed by primary care givers (Appendix II). Primary care givers were requested to avail themselves for an interview at a place that one felt comfortable. Interviews were done in private, codes identification was used. Consent forms and filled questionnaires were kept under key and lock to ensure high level of confidentiality and privacy. Primary care giver participation was voluntary and the respondents had opportunity to refuse to be involved in the study or withdraw from the study at any point without penalty. The researcher did not

anticipate any risks or discomforts during this study. There was no direct benefit to client. However the finding of the study may be beneficial to the relevant officers in motivating relevant program that will go a long way in enhancing adherence to scheduled medical appointment among children on HIV care services. There was no cost for participating in this study.

3.10 Strengths

The respondents participated in study fully. HIV Care being provided at KNH CCC is per recommended clinical practice guidelines. Services being considered under adherence to scheduled care appointment can be argued to be generalizable across hospital settings.

3.11 Study Limitations

KNH CCC often receives referrals from across the country and these are often very sick requiring admission and specialized care leading to prolonged duration of recruitment of participants.

3.12 Validity

To test the validity of the instrument, a pretest of the data collection tools was done at Nairobi CCC which has a system almost similar to the CCC, KNH. 10% (23) of the questionnaires were used to assess the reliability of the questionnaires. The collected data was analyzed, summarized and findings were disseminated to the CCC providers of the facility. This data was not included in the main study results. Validity was conducted to determine the suitability, appropriateness, and clarity of the questionnaire items in addressing the variables under investigation that needed attention and the errors in the questionnaires was addressed.

3.13 Data Reliability

The study tools which were used were standardized for all the children care givers such as a semi structured questionnaire.

CHAPTER FOUR

RESULTS

4.1 Demographics Characteristics of Children Caregivers

The study recruited 221 caregivers of children whom majorities were female 190 (86%) and married 139 (62.9%). Majority of the caregivers were self-employed 87 (39.4%). Majority 148 (66.9%) had secondary education and above. Most of caregivers were aged 30 years and above 161(72%). (Table 4.1).

Table 4.1: Demographics Characteristics of Children Caregivers

Characteristics of care		Frequency	0/0
giver		NO	
Sex			
	Male	31	14.0%
	Female	190	86.0%
Age group of care giver			
	18-24	13	5.9%
	25-29	47	21.3%
	30-34	71	32.1%
	35-39	48	21.7%
	>=40	42	19.0%
Marital status			
	Single	42	19.0%
	Married	139	62.9%
	Divorced/separated	25	11.3%
	Widow/widower	15	6.8%
Source of income			
	Full time formal employment	54	24.4%
	Part time employment	40	18.1%
	Self employed	87	39.4%
	Unemployed	40	18.1%
Average monthly income	•		
	< 5000	45	20.4%
	5001-10000	64	29.0%
	10001-20000	51	23.1%
	20001-30000	35	15.8%
	30001-40000	9	4.1%
	40001-50000	7	3.2%
	50001-60000	5	2.3%
	>60000	5	2.3%
Highest level of education			
-	No formal education	2	0.9%
	Primary level	71	32.1%
	Secondary level	98	44.3%
	University/College	50	22.6%

4.2 Care giver relationship with the child and duration of children has been on HIV Care

Majority of children care givers were their mothers 165 (74.7%). Most of the children 1-3: 217 (98.2%) were being taken care by the care giver

Table 4.2: Care giver relationship with the child and duration of children has been on HIV Care

Characteristics	Frequency (NO)	Percentage %
Relationship with children		
Parent Mother	165	74.7
Parent Father	29	13.1
Grandmother	6	2.7
Aunt	9	4.1
Uncle	1	0.5
Brother/Sister	2	0.9
Other relative	2	0.9
Foster care	7	3.2
Children under primary caregiver		
1-3	217	98.2
>4	4	1.8

4.3 Children care giver who were receiving HIV care services

Children care giver who were receiving HIV care and treatment services were 184(83.3%) at baseline while 37(16.7%) were not on HIV care and treatment. (Figure 4.1).

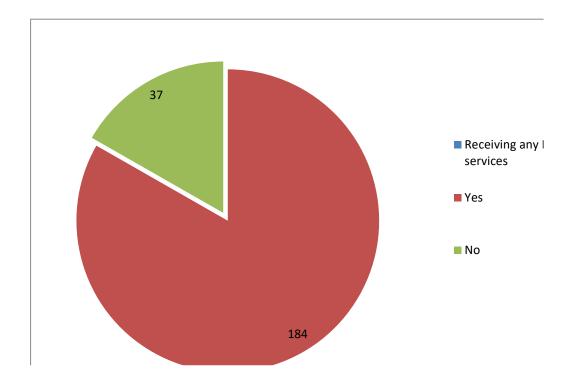


Figure 4.1: Child care giver who were receiving HIV care services

4.4 Demographics Characteristics of Children

Male were 113 (51.3%) slightly higher than female, Most of the children have been on HIV care for the duration of three years and more 142 (64.6%). (Table 4.3).

Table 4.3: Demographics Characteristics of Participants - Children

Characteristics	Frequency NO	Percentage (%)
Sex		
Male	113	51.1
Female	108	48.9
Duration a child has been on HIV care		
<1 year	26	11.8
2 years	52	23.6
3 years	46	20.9
4 years	16	7.3
>5 years	80	36.4

4.5. Children Clinical Characteristics and services provided during scheduled medical appointments at baseline

The findings of this study show that the median Interquartile range (IQR) of CD4 count was 1067 (788-1542) and median (IQR) viral load 0 (0-374). Majority of children were classified in stage 1 or 2 of World Health Organization 212 (95.9) at baseline. The least utilized support services reported were psychosocial support and nutritional services used by <20 of the respondents. Perceived benefits was the main factor reported by majority of care givers as a factor promoting adherence to care among children at baseline 143 (64.7%). (Table 4.4).

Table 4.4: Children Clinical Characteristics and services provided during scheduled medical appointments at baseline

Variables		Baseline n	(%)
Children cl	inical characteristics		
CD 4count	Median (IQR)	1067	[788-1542]
Viral load	Median (IQR)	0	[0-372]
WHO HIV	staging of children		
1	or 2	212	(95.9)
3 (or 4	9	(4.1)
HIV care su	apport services received		
H	IV care counselling	31	(14.2)
Psych-social support		18	(8.1)
Tr	reatment of	32	(14.5)
O _l	pportunistic infection		
Al	RT refill	212	(95.9)
Nı	utrition services	9	(4.1)
La	aboratory services	44	(19.9)
Factors pro	moting adherence to ca	re	
Fr	ee drugs	105	(47.5)
Nı	utrition support services	17	(7.7)
Ad	dherence counselling	51	(23.1)
Pe	erceived benefit	143	(64.7)

4.6. Children Clinical Characteristics and services provided during scheduled medical appointments at 6 months of follow up.

The findings of this study show that the median Interquartile range (IQR) of CD4 count was 1090 (842-1484) and median (IQR) viral load 0 (0-68). Majority of children were classified in stage 1 or 2 of World Health Organization 212 (98.6) at baseline. The least utilized support services reported were psychosocial support and nutritional services used by <20 of the respondents. Perceived benefits was the main factor reported by majority of care givers as a factor promoting adherence to care among children at baseline 154 (71%). Child missed HIV treatment because drugs had finished were 11 (5.1%), while 34 (15.7%) of children were treated for other illness as outpatient not HIV. (Table 4.5).

Table 4.5. Children Clinical Characteristics and services provided during scheduled medical appointments at 6 months follow up

Variables		At 6 months	%
		n	
Children clinical chara	cteristics		
CD 4count	Median (IQR)	1090	[842-1484)
Viral load	Median (IQR)	0	[0-68]
WHO HIV staging of c	hildren		
	1 or 2	214	98.6
	3 or 4	3	1.4
HIV care support servi	ces received		
	HIV care counselling	72	33.2
	Psych-social support	27	12.4
	Treatment of	16	7.4
	Opportunistic infection		
	ART refill	213	98.2
	Nutrition services	33	15.2
	Laboratory services	116	53.5
Factors promoting adh	erence to care		
	Free drugs	131	60.4
	Nutrition support	22	10.1
	services		
	Adherence counselling	77	35.5
	Perceived benefit	154	71
	tment because drugs had		
finished			
	Yes	11	5.1
	No	206	94.9
Child treated for other HIV	illness as outpatient not		
•	Yes	34	15.7
	No	183	84.3

4.7 Children Clinical Characteristics and services provided during scheduled medical appointments at 12 months of follow up

The findings of this study show that the median Interquartile range (IQR) of CD4 count was 1077 (780-1592) and median (IQR) viral load 0 (0-47). Majority of children were classified in stage 1 or 2 of World Health Organization 209 (96.8) at 12 months of follow up. The least utilized support services reported were psychosocial support and nutritional services used by <20% of the respondents.

Perceived benefits was the main factor reported by majority of care givers as a factor promoting adherence to care among children at 12 months of follow up 162 (75%). Post follow-up at 12 months 9 (4%) of the children missed their medication because their drugs had finished. Child treated for other childhood illness other than HIV as outpatient 42 (19.4%) (Table 4.6).

Table 4.6: Children Clinical Characteristics and services provided during scheduled medical appointments at 12 months follow up

Variables		At 12months	
		n	%)
Children clinic	cal characteristics		
CD 4count	Median (IQR)	1077	[780-
		1592]	
Viral load	Median (IQR)	0	[0-47]
WHO HIV sta	iging of children		
1 or 2		209	(96.8)
3 or 4		7	(3.2)
HIV care supp	ort services received		
HIV	care counselling	42	(19.4)
Psych	n-social support	26	(12.0)
Treat	ment of Opportunistic	26	(12.0)
infect	ion		
ART	refill	212	(98.1)
Nutrition services		11	(5.1)
Laboratory services		102	(47.2)
Factors promo	ting adherence to care	2	
Free o	drugs	129	(59.7)
Nutri	tion support services	33	(15.3)
Adhe	rence counselling	44	(20.4)
Perce	ived benefit	162	(75.0)
Child missed H	HIV treatment because	drugs had finishe	d
Yes		9	(4.2)
No		207	(95.8)
Child treated f	or other illness as out	patient not HIV	
Yes	•	42	(19.4)
No		174	(80.6)

4.8 Challenges encountered by primary care givers on ensuring their children are adhering to scheduled medical care appointment

The challenges encountered by primary care givers on ensuring their children were adhering to scheduled medical care appointment at 12 months of follow up are; long distance, 59 (27.3%), perceived stigma 47 (21.8%) and financial burden 59 (27.3%), Table 4.4. The challenges of finances, distance and stigma hinder adherence to scheduled medical appointment and was noted in Focused group discussion.

"I do wages and if there is no work. I do not get transport money for vehicle. Because the first thing is to buy food" "the place I live is far away and transport cost is very high and I can't walk while carrying a child. A 30 years man said, "I fear to be seen by those who know me at HIV clinic"

Table 4.7: Challenges encountered by primary care givers on ensuring their children are adhering to scheduled medical care appointment

Challenge encountered by	Baseline	at 6 months	At 12 months		
primary care givers	n%	n%	n%		
Different appointment date for	3(1.4)	4(1.8)	1(0.5)		
children and caregiver					
Long waiting time	42(19.0)	33(15.2)	33(15.3)		
Long Distance	51(23.1)	40(18.4)	59(27.3)		
Frequent clinic attendance	7(3.2)	8(3.7)	1(0.5)		
Finance burden	53(24.0)	67(30.9)	59(27.3)		
Family conflict	3(1.4)	9(4.1)	7(3.2)		
Perceived stigma	34(15.4)	36(16.6)	47(21.8)		
Male partner support	17(7.7)	8(3.7)	1(0.5)		
Forgetfulness of appointment	8(3.6)	6(2.8)	5(2.3)		
date					
Perception of child health	3(1.4)	5(2.3)	3(1.4)		
Religious Belief	(0)	(0)	(0)		

4.9 Children scheduled medical appointments

The children who participated in the study at baseline were 221, six months 217 and 216 at 12 months during study period. Children receiving HIV care at Comprehensive Care Centre were scheduled medical appointment ranging from one

to five and more during study period. Majority of children were scheduled two appointment at six months 163(75%) and 175 (81%) at 12 months of follow up. Few children were scheduled appointment more than 5 times 5 (2.3%) at six months and 5 (2,3%) 12 months respectively (Table 4.8).

Table 4. 8: Children scheduled medical appointments during study period

Number	of Medical	Baseline	At six months	At 12months
appointme	nt scheduled	n(%)	Follow up n(%)	Follow up n (%)
One		2(0.9)	9(4.1)	4(1.9)
Two		6(2.7)	163(75.1)	175(81.0)
Three		18(8.1)	32(14.7)	27(12.5)
Four		145(65.6)	8(3.7)	5(2.3)
>5		50(22.6)	5(2.3)	5(2.3)

4.10 Adherence of children to scheduled medical appointment

This study found adherence to scheduled HIV medical appointment among study participants to be 81.9% at 12 months of follow up (Table 4.9). From the qualitative findings, most care givers recognized the value and importance of adhering to scheduled medical appointments. "It is very important to take our children to the clinic... Adherence to scheduled medical appointment was defined as a child not missing any scheduled medical appointments.

Table 4. 9: Adherence of children to scheduled medical appointment

Missed Medical appointment scheduled	Baseline n(221)	At six months Follow up n(217)	At 12 months Follow up n(216)
1	44(19.9)	43(19.8)	35(16.2)
2	10(4.5)	7(3.2)	4(1.9)
None	167(75.6)	167(77.0)	177(81.9)

4.11 Social demographic characteristics of care giver associated with adherence to scheduled medical appointment at baseline

This study found that the age, gender, marital status and level of education of primary care givers were not significantly associated with adherence to scheduled medical appointment among their children (Table 4.10).

Table 4. 10: Social demographic characteristics of care giver associated with adherence to scheduled medical appointment at baseline

Varial	bles	Descriptive	95% CI	P Value
Sex of	care giver	_		
	Male	31(14.0)	Ref	
	Female	190(86.0)	0.53 (0.24 - 1.20)	0.471
Age	Mean (SD)	33[29-38]		
Age gr	oup of care giver			
	18-24	13(5.9)	Ref	
	25-29	47(21.3)	4.11 (0.48 - 35.07)	0.479
	30-34	71(32.1)	2.69 (0.32 - 22.56)	0.246
	35-39	48(21.7)	5.45 (0.65 - 45.87)	0.188
	>=40	42(19.0)	5.38 (0.63 - 45.83)	0.056
Marita	l status	•	•	
	Single	42(19.0)	Ref	
	Married	139(62.9)	1.10(0.48-2.53)	0.802
	Divorced/separated	25(11.3)	1.16(0.36-3.76)	0.286
	Widow/widower	15(6.8)	3.21(0.92-11.24)	0.324
Source	e of income			
	Full time formal employment	54(24.4)	Ref	
	Part time employment	40(18.1)	1.13(0.42-3.07)	0.594
	Self employed	87(39.4)	1.49(0.66-3.35)	0.857
	Unemployed	40(18.1)	1.30(0.49-3.45)	0.915
Averas	ge monthly income	,	,	
	<5000	45(20.4)	Ref	
	5001-10000	64(29.0)	0.36(0.14-0.93)	0.416
	10001-20000	51(23.1)	0.84(0.35-2.02)	0.884
	20001-30000	35(15.8)	0.89(0.34-2.33)	0.199
	30001-40000	9(4.1)	1.77(0.41-7.62)	0.442
	40001-50000	7(3.2)	0.63 (0.07-5.92)	0.686
	50001-60000	5(2.3)	1.48(0.22-9.84)	0.404
	>60000	5(2.3)	0.55(0.06-5.41)	0.89
Highes	st level of education	, ,	,	
0	No formal education	2(0.9)	Ref	
	Primary level	71(32.1)	1.81(0.79-4.15)	0.302
	Secondary level	98(44.3)	0.85(0.37-1.97)	0.191
	University/College	50(22.6)	0.43(0.03-7.31)	0.558

4.12 CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at Baseline

Children who were not treated for opportunistic infections had 0.35 decreased odds of adhering to scheduled medical appointment (95% CI 0.16 – 0.76) as compared to those treated for opportunistic infections. Children who were not done laboratory test had 0.49 decreased odds of adhering to medical appointment (95% CI 0.25 – 0.97) as compared to those who have been done laboratory test. Children who have been on care for 3 years were16 times (95% CI 2.00- 129.24) more likely to adhere to scheduled medical appointments when compared to those who have been on care for >1 years. Children who have been on care for >5 years were 9 times (95% CI 1.13-69.81) more likely to adhere to scheduled medical appointments when compared to those who have been on care for >1 years. Children with a high viral load (>=10 000 copies/ml) were 5.6 times (95% CI 2.27- 13.84) more likely to adhere to scheduled medical appointments when compared to those with undetectable viral load. Other factors: number of medical appointment scheduled, CD4 count, psychosocial support during HIV care, WHO staging of the child and whether caregiver received HIV care were not significantly associated with adhering to HIV care. (Table 4.11).

Table 4.11: CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at Baseline

		Missed appointm	nent		
		Yes (n=54)	No	OR (95% CI)	P value
			(n=167)		
Medical appointm	ent schedul	ed			
	One	1(1.9)	1(0.6)	Ref	
	Two	0(0.0)	6(3.6)		
	Three	1(1.9)	17(10.2)	0.06(0.00-1.81)	0.105
	Four	36(66.7)	109(65.3)	0.33(0.02-5.42)	0.438
	>5	16(29.6)	34(20.4)	0.47(0.03-8.01)	0.602
CD 4 categories					
	0	7(13.0)	15(9.0)	Ref	
	500	26(48.1)	47(28.1)	1.19()	0.743
	1000	14(25.9)	49(29.3)	0.61(0.21-1.80)	0.371
	1500	3(5.6)	24(14.4)	0.27(0.06-1.20)	0.085
	2000	4(7.4)	24(14.4)	0.36(0.09-1.43)	0.146
HIV care psychoso		.(,,	21(11.1)	0.50(0.0) 1.15)	0.1 10
support	, ciui				
	Yes	7(13.0)	11(6.6)	Ref	
	No	47(87.0)	156(93.4)	0.47(0.17-1.29)	0.144
HIV care treatmen		.,(0,.0)	150(55.1)	5.17(0.17 1.29)	V.1.11
opportunistic Infe					
opportumente ime	Yes	14(25.9)	18(10.8)	Ref	
	No	40(74.1)	148(88.6)	0.35(0.16-0.76)	0.008
How long child ha		, ,	140(00.0)	0.55(0.10-0.70)	0.000
now long clind ha	<1 year	1(1.9)	25(15.0)	Ref	
	2 years	12(22.2)	40(24.0)	7.50(0.92-	0.060
	2 years	12(22.2)	40(24.0)	61.26)	0.000
	3 years	18(33.3)	28(16.8)	16.07(2.00-	0.009
	3 years	10(33.3)	20(10.0)	129.24)	0.009
	4 years	1(1.9)	15(9.0)	1.67(0.10-	0.725
	4 years	1(1.9)	13(9.0)	28.66)	0.723
	. 5	21/29 (1)	50(25.2)		0.038
	>5	21(38.9)	59(35.3)	8.90(1.13-	0.038
Dagairra any IIIV	years			69.81)	
Receive any HIV o		41(75.0)	143(85.6)	Dof	
	Yes	41(75.9)	` ′	Ref	0.100
G•	No	13(24.1)	24(14.4)	1.89(0.88-4.04)	0.100
Service encouraging	ng adnerend	e iaboratory			
testing	Vac	19(22.2)	22(10.9)	Dof	
	Yes	18(33.3)	33(19.8)	Ref	0.042
Vinel leed	No	36(66.7)	134(80.2)	0.49(0.25-0.97)	0.042
Viral load					
categories	0	20(55.6)	100/71 0	Dof	
	0	30(55.6)	120(71.9)	Ref	0.200
	100	2(3.7)	21(12.6)	0.38()	0.209
	1000	7(13.0)	13(7.8)	2.15(0.79-5.87)	0.133
	10000	14(25.9)	10(6.0)	5.60(2.27-	< 0.001
*****				13.84)	
WHO staging of					
child					
	1 or 2	50(92.6)	162(97.0)	Ref	
	3 or 4	4(7.4)	5(3.0)	2.59(0.67-	0.168
				10.02)	

4.14 CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at Baseline at Multivariable analysis

Children who have been on care for three years were 35 times (95% CI 3.15—390.99) more likely to miss the scheduled clinic appointments when compared to those who have been on care for >1 years. Children who have been on care for >5 years were 18.6 times (95% CI 1.75- 198.2) more likely to miss scheduled clinic appointments when compared to those who have been on care for >1 years.similar trend observed among those aged two years. Children who were treated for opportunistic infections or not had the same risk of adhering to scheduled clinic appointment 0.38 (95% CI 0.14 – 1.0). Children with a high viral load (>=10 000 copies/ml) were 9 times (95% CI 2.63- 30.78) more likely to miss scheduled clinic appointments when compared to those with 0-99 viral load (Table 4.12). Other factors like encouraging using laboratory services is not a predictor of adherence to scheduled clinic appointment.

Table 4.12: CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at Baseline at Multivariable analysis

Missed appointment				
	AOR	95% CI		P value
Treated for opportunistic infection				
Yes	1			
No	0.38	0.14	1.00	0.05
Encouraged to use lab services				
Yes	1.00			
No	0.57	0.25	1.27	0.168
Viral load categories				
0-99	1.00			
100-999	0.36	0.07	1.76	0.207
1000-9999	2.42	0.76	7.68	0.134
>=10000	8.99	2.63	30.78	0
Duration in care in KNH				
<1 year	1.00			
2 years	17.54	1.53	201.26	0.021
3 years	35.11	3.15	390.99	0.004
4 years	5.18	0.23	116.45	0.301
>5 years	18.64	1.75	198.20	0.015

4.15 CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at six months of follow up

Children who were not treated for opportunistic infections had 0.15 decreased odds of missing scheduled medical appointment (95% CI 0.05 – 0.45) as compared to those who were treated for opportunistic infections. Children who had not been treated for other childhood illness as outpatient had 0.42 decreased odds of missing scheduled medical appointment (95% CI 0.19 – 0.92) as compared to those who were treated for other childhood illness as outpatient. Children with a high viral load (>=10 000 copies/ml) were 6.38 times (95% CI 2.19- 18.57) more likely to miss the scheduled medical appointments when compared to those with low viral load (0-99 copies/ml). Other factors: CD4 count, psychosocial support during HIV care, WHO staging of the child ,Child missed HIV treatment because drugs had finished were not significantly associated with adhering to scheduled medical appointments (Table 4.13).

Table 4.13: CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at six months of follow up

		Missed appoi	intment		
Variable		Yes (n=51)	No	OR (95% CI)	P value
			(n=166)		
CD 4 categories					
	0-499	3(5.9)	10(6.0)	Ref	
	500-999	25(49.0)	55(33.1)	1.52()	0.553
	1000-1499	14(27.5)	55(33.1)	0.85(0.21-3.50)	0.82
	1500-1999	1(2.0)	18(10.8)	0.19(0.02-2.02)	0.167
	< 2000	8(15.7)	24(14.5)	1.11(0.24-5.07)	0.892
HIV care psychosoc	cial support				
	Yes	6(11.8)	21(12.7)	Ref	
	No	45(88.2)	145(87.3)	1.09(0.41-2.86)	0.867
HIV care treatment	of Opportunistic	Infection			
	Yes	10(19.6)	6(3.6)	Ref	
	No	41(80.4)	160(96.4)	0.15(0.05-0.45)	0.001
Child missed HIV t	reatment drugs				
finished		- (- a)	0.44.00		
	Yes	3(5.9)	8(4.8)	Ref	0.7.0
	No	48(94.1)	158(95.2)	0.81(0.21-3.17)	0.763
Received HIV care	in other health				
care facilities					
	Yes	7(13.7)	10(6.0)	Ref	
	No	44(86.3)	156(94.0)	0.40(0.14-1.12)	0.081
Child treated for other					
illness other than H	IV as outpatient				

	Yes	13(25.5)	21(12.7)	Ref	0.02
X7:111	No	38(74.5)	145(87.3)	0.42(0.19-0.92)	0.03
Viral load categories					
	0-99	28(54.9)	139(83.7)	Ref	
	100-499	6(11.8)	16(9.6)	1.86()	0.233
	1000-999	9(17.6)	7(4.2)	6.38(2.19-	0.001
				18.57)	
	<10000	8(15.7)	4(2.4)	9.93(2.8-	< 0.001
				35.25)	
WIIO stars	1 2	40(06.1)	165(00.4)	D-f	
WHO stage	1 or 2	49(96.1)	165(99.4)	Ref	
WHO stage	3 Or 4	2(3.9)	1(0.6)	6.73(0.60-	0.123
				75.85)	

4.15 CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at six months of follow up at multivariable analysis

This study found that children who had never missed treatment because drugs had finished had decreased odds of missing scheduled medical appointments as compared with children who had missed treatment because drugs had finished (0.09 (95% CI 0.01-0.60). P < 0.013. This study found increasing trend for higher odds of missing scheduled medical appointments with an increase in CD4 counts aOR 16.27 (95% CI 2.36 – 111.97) CD4 1000 – 1499; 19.40 (95% CI 3.33 – 113.19) CD4 >=1500 when compared to children with <500 CD4 count. HIV care treatment of Opportunistic Infection was not significantly associated with adherence to scheduled medical appointments among study participants. Table 4.14.

Table 4.14: CD4 counts and services associated with adherence to scheduled medical appointments among HIV infected children at six months of follow up at multivariable analysis

Missed appointment	Odds	95% Confidence		P	LRT	0.013
	Ratio	interva	interval			
CD 4 categories						
0- 499	1.00					
500-999	3.14	0.99	9.93	0.051		
1000-1499	16.27	2.36	111.97	0.005		
1500-1999	19.40	3.33	113.19	0.001		
Child missed HIV treatment						
because drugs had finished						
Yes	1.00					
No	0.09	0.01	0.60	0.013		
HIV care treatment of Opportunistic						
Infection						
Yes	1					
No	0.32	0.09	1.17	0.086		

4.16 Children clinical factors associated with adherence to scheduled medical appointment among HIV infected children aged 18 months to nine years receiving HIV care services at KNH, at 12 months of follow up

Children with a high viral load (>=1000 copies/ml) had 39 times (95% CI 7.62-199.58) increased Odds of missing the scheduled medical appointments when compared to those with low viral load (0-99 copies/ml). Children who were on WHO stage 3 and 4 had 12.87 increased odds of missing scheduled medical appointment (95% CI 2.4 – 69.07) as compared to those who was at WHO stage 1 and 2. Children who were not treated for opportunistic infections had 0.09 decreased odds of missing scheduled medical appointment (95% CI 0.03 – 0.21) as compared to those who were treated for opportunistic infections. This study found that children who had never missed treatment because drugs had finished had decreased odds of missing scheduled clinic appointments as compared with children who had missed treatment because drugs had finished (0.05 (95% CI 0.01-0.26). P < 0.0001. Children who had not received HIV treatment in other health facility had 0.16 decreased odds of missing scheduled medical appointment) (95% CI 0.05 – 0.51) as compared to those who received HIV care in other health facility. Other factors: CD4 counts and

psychosocial support during HIV care were not significantly associated with adherence to scheduled medical appointments (Table 4.15).

Table 4.15: Children clinical factors associated with adherence to scheduled medical appointments among HIV infected children at 12 month follow up

		Missed ap Yes	pointment		
Variable		(n=39)	No (n=177)	OR (95% CI)	P value
CD 4 categories		(/	, , ,		
· ·	0-499	3(7.7)	11(6.2)	Ref	
	500-999	18(46.2)	60(33.9)	1.10()	0.892
	1000-				
	1499	6(15.4)	56(31.6)	0.39(0.09-1.81)	0.231
	1500-				
	1999	4(10.3)	23(13.0)	0.64(0.12-3.36)	0.595
	>2000	7(17.9)	23(13.0)	1.12(0.24-5.16)	0.888
HIV care psychosocia support	ıl				
	Yes	8(20.5)	18(10.2)	Ref	
	No	31(79.5)	159(89.8)	0.44(0.18-1.10)	0.078
HIV care treatment of Opportunistic Infection		(() ()	(,	(2. 2	
- F F	Yes	16(41.0)	10(5.6)	Ref	
	No	23(59.0)	167(94.4)	0.09(0.03-0.21)	< 0.001
Child missed HIV treat finished	ment drugs	- (,		,	
	Yes	7(17.9)	2(1.1)	Ref	
	No	32(82.1)	175(98.9)	0.05(0.01-0.26)	< 0.001
Received HIV care in of facilities	other health				
	Yes	7(17.9)	6(3.4)	Ref	
	No	32(82.1)	171(96.6)	0.16(0.05-0.51)	0.002
Child treated for other illness other than HIV as		` ,	` ,	, ,	
	Yes	21(53.8)	21(11.9)	Ref	
	No	18(46.2)	156(88.1)	0.12(0.05-0.25)	< 0.001
Viral load categories					
	0-99	16(41.0)	156(88.1)	Ref	
	100-				
	999	5(12.8)	17(9.6)	2.87()	0.066
	1000-	•		39.00(7.62-	
	9999	8(20.5)	2(1.1)	199.58)	< 0.001
				48.75(9.81-	
	>10000	10(25.6)	2(1.1)	242.18)	< 0.001
WHO stage	1or 2	34(87.2)	175(98.9)	Ref 12.87(2.40-	
WHO stage	3 or 4	5(12.8)	2(1.1)	69.07)	0.003

4.17 Children clinical factors associated with adherence to scheduled medical appointments among HIV infected children at 12 months during study period

There was an increasing trend for higher odds of missing scheduled medical appointments with an increase in CD4 counts aOR 19.32 (95% CI 2.73 - 136.78) CD4 1000 - 1499; 21.48 (95% CI 3.64 - 126.62) CD4 >=1500 when compared to children with <500 CD4 count. This study found that children who had never missed treatment because drugs had finished had 0.08 decreased odds of missing scheduled medical appointments as compared with children who had missed treatment because drugs had finished ((95% CI 0.01-0.54). PV <0.01. Children who had not received HIV treatment in other health facility had 0.22 decreased odds of missing scheduled medical appointment) (95% CI 0.05 - 0.96) as compared to those who received HIV care in other health facility. HIV care treatment of Opportunistic Infection was not significantly associated with missing scheduled medical appointments. Table 4.16

Table 4.16: Children clinical factors associated with adherence to scheduled medical appointments among HIV infected children at 12 months during study period

Missed	Odds	95% Confidence interval		P	LR	0.05
appointments	Ratio			value	T	5
CD 4 categories						
0-499	1					
500 -999	3	0.93	9.65	0.066		
1000 -1499	19.32	2.73	136.78	0.003		
≥ 1500	21.48	3.64	126.62	0.001		
Child missed HIV tro	eatment becau	ise drugs had fii	nished			
Yes	1					
No	0.08	0.01	0.54	0.01		
HIV care treatment	of Opportunis	tic Infection				
Yes	1(ref)					
No	0.39	0.11	1.47	0.167		
Received HIV care in	n other health	facilities				
Yes	1					
No	0.22	0.05	0.96	0.044		

4.18 Care givers perceptions associated with adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya.

Benefit of HIV care services provided to HIV infected children

During the FGD among care givers the following benefit of HIV care services provided to their children during scheduled medical appointments were identified as follows: Children are in good health and attend school classes without problem. Children are rarely admitted to the hospital. Majority of caregiver pointed out that HIV cares services provided to their children are very beneficial to their health.

Children are in good health and attend school classes without problems.

"The primary care giver said, since I started receiving HIV care services and adhering to scheduled medical appointment my child now attends all school classes without problem",,,,(FGD, 2).

"Our children these days they don't miss attendances of classes due to HIV related infection, we are very happy as our children can continue with schooling programme without problem".... (FGD,1).

Our children are not admitted to the hospital

"Our children who are on HIV care services have reduced number of admission to the hospital" some of us, we have forgotten hospital admission due to HIV infection".... (FGD,1).

"We thank the HIV prevention team, for providing us with free drugs which has contributed to reduction of hospital admission to our children" (FGD, 2).

Very beneficial to a child's health

Most care givers recognized the value and importance of adhering to scheduled clinic appointments. "Majority of caregiver pointed out that HIV cares services provided to their children are very beneficial to their health, and now their live quality life" (FGD, 2).

Our children are growing normally like other children without HIV" (FGD,1). "It is very important to take our children to the scheduled medical appointment, so that we reduce death and development of opportunistic infection which requires frequent hospital admission" (FGD, 2).

Perception of Caregivers on factors motivating adherence to scheduled medical appointment

From the qualitative findings (FGD), most care givers perceive the following factors as motivating to adherence to scheduled medical appointment among their HIV infected children; HIV care services provided to their HIV infected children leading to non-detectable viral load, caregiver taking short time in the medical clinic and Having friendly health care workers who understands our situation.

HIV care services provided to their HIV infected children leading to nondetectable viral load,

The children caregivers appreciate the HIV care services provided to their HIV infected children such, drug refilling, laboratory investigation and treatment of opportunistic infection which motivate them to take their children to scheduled medical appointment thus leading to non-detectable viral load of their children.

",,,,In this HIV clinic our children are provided with very good HIV care services, our children has recovered energy their can perform activities like other normal children and always drugs are available which has resulted to non-detectable viral load of our children" (FGD, 2).

"Our children are very health since we started coming to this clinic, we will continue adhering to scheduled medical appointment of our children." (FGD, 1).

Taking short time in the medical clinic and having friendly health care providers

Caregivers were satisfied with services provided as they are received by friendly health care providers who were encouraging them to attend all scheduled medical appointment. The HIV infected children are provided with the services within short time in the clinic.

"Caregivers reported that we are receiving friendly health care services from our care providers. They communicate to us with respect and listen and respond to our question with good attitude. They not stigmatize us. Currently we are taking very short period of time to receive all HIV care services for our children "(FGD, 1).

"We take very short time in the clinic and we return back home to continue with our duties. These days care providers are always ready and available to provide HIV care services to us, they start clinic very early." (FGD, 1).

Care givers challenges associated with adhering to scheduled medical appointments

Caregivers perceive, distance to the clinic, transport cost and perceived stigma and discrimination and health status of the child as the challenges associated with adhering to scheduled medical appointment.

"....We do wages and if there is no work...We don't get transport money for vehicle...because the first thing is to buy food" (FGD, 2)

"The place we live is far away and transport cost is very high and we can't walk while carrying a child" (FGD,1)

"Some caregivers interpret high CD4 cell counts to mean improved health and thus influencing their decision negatively to take their children to the scheduled medical appointments" (FGD,2).

Some of the proposed solutions to promote adherence to scheduled medical appointments included: Reducing the number of scheduled appointments, Synchronizing appointments with school holidays for students reducing waiting time in the clinic and financial support to offset transport costs.

"We are saying if the number of scheduled medical appointments are reduced it will lead to increased adherence to scheduled medical appointment as we are required to come to HIV clinic few times in the year...." (FGD,2)

"We need our health care providers to schedule our clinic the same day with our children on our HIV care during school holidays and mostly where both us are HIV positive" (FGD,1)

"If we get financial support to cater for transport expenses, we are likely to adhere to scheduled medical appointment" (FGD,2)

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Demographics Characteristics of Children Caregivers

This study was a 12 -month's follow-up study where 221 caregivers of children were recruited. The demographic characteristics of the children caregivers in this study were; Majority of caregivers of children were female 190 (86%) this shows mostly the burden of taking the children to scheduled medical appointment relies with female. This shows health care workers should put strategies to improve male involvement in the care of children. Study done by Wagner et al. (2015) has found similar findings to our study that majority of children are taken to scheduled medical appointment by female. This study has found 139 (62.9%) of caregivers of HIV infected children were married. These findings are similar with those of Mchugh et al.,2017). This study found majority of the caregivers were self-employed 87 (39.4%), This shows the nature of employment of the care givers influence the level of adherence to scheduled medical appointment. These findings were consistent with study done by Wachira et al., (2012) who found out that majority of care givers were self-employed and thus they have to close their business to take their children to medical appointment. This is one of the reasons why children caregivers like to take shortest time possible to the medical clinic so that they can return back to their business or jobs.

Current study found out that most of the children caregivers were 148 (66.9%) had secondary education and above. This shows our care givers are learned and therefore they can easily understand the instructions on issues related with adherence to scheduled medical appointment. Study done by Horwood *et al.*, (2010) among children found majority of children care givers had secondary education and above and thus can follow HIV treatment regime effectively. Current study found out that most of children caregivers were aged 30 years and above. This is consistent with the study done by (Brennam *et al.*,2010).

5.2 Adherence to scheduled medical Appointment among HIV infected children

This study found out that scheduled medical appointment attendance was adhered to at different time intervals 77% (167) 81.9% (177) at 6 month and 12 months of care respectively. The results is comparable to study done in USA on HIV clinic attendance which found out the majority of patient attended 76% of their scheduled appointments (Walburn *et al.*, 2012). The study done by Braistein *et al.*, (2011) found that the adherence rate of children on regular HIV clinic attendance is higher in the first 12 months about 82% and reduces to about 61% at month 60. Missed scheduled clinic visits is a risk factor for negative outcome for HIV positive patient. Adherence to regular medical appointments among the children in HIV program is significant in improving their health outcome (Wachira *et al.*, 2012). Missed scheduled medical clinic appointments are risk factors for opportunistic infections, AIDS-defining illness, and mortality among children (Nijhawan *et al.*, 2016).

The challenges of finances, long distance and perceived stigma to promote adherence to care was noted in Focused group discussion. "I do wages and if there is no work..... I do not get transport money for vehicle. because the first thing is to buy food" "the place I live is far away and transport cost is very high and I cant walk while carrying a child. Regular clinic attendance for HIV care is important for successful clinical outcomes in HIV treatment More sore timeliness for clinic appointments attendance has been found to be positively correlated with better outcomes amongst patients on HIV treatment (Mugavero *et al.*, 2009). According to Park *et al.*, (2007) study pointed out that adherence to scheduled clinic appointments visits is associated with clinical improvement regardless of status of children on initiation of HIV treatment. Children who attend HIV clinic regularly have the opportunity to be treated for HIV-related diseases early hence reduced morbidity and mortality.

HIV-infected children who missed scheduled clinic visits may also miss taking their antiretroviral drugs. Inconsistent clinic attendance among HIV infected children may help identify children in need of adherence counselling (Chalker *et al*, 2010). In developed countries, poor clinic attendance has been shown to be correlated with

High mortality (Osterberg and Blaschke, 2005). Missed clinic appointment has also been shown to be a strong predictor for virological failure (Bastard *et al.*, 2012). Regular HIV clinic attendance plays a key role in prolonging life and enhancing quality of life for people living with HIV/AIDS (Park *et al* 2007). According to Park *et al.*, (2007) the number of missed clinic visit is directly related to the rate of disease progression. Missed clinic appointment should trigger concern about patients at risk of defaulting on their care. Attending clinic appointment at scheduled time has been demonstrated to be positively correlated with better HIV outcome among patient. Missed attendance to medical clinic is seen among children due to their dependency on their primary caregiver to bring them to attend scheduled medical appointments (Schneiderman *et al.*, 2016).

5.3 The association between CD4 count and adherences to scheduled medical appointments among HIV infected children

This study found out that the CD4 counts are associated with adherence to scheduled medical appointment among the study participants. At 12 months of follow up there was an increasing trend for higher odds of missing scheduled medical appointments with an increase in CD4 counts aOR 19.32 (95% CI 2.73 – 136.78) CD4 1000 – 1499 ; 21.48 (95% CI 3.64 - 126.62) CD4 >= 1500 when compared to children with < 500CD4 count. Similar estimates and trends were observed at six months follow-up. This shows as the child improves while on care the CD4 Counts increases which trigger some caregiver to fail to take their children to clinic as they perceive their children has healed. The higher the CD4 counts the lower the likelihood of adherence to scheduled medical appointments. This is consistent with findings from Braintstein et al., (2011), Horstman et al. (2010) that pointed out high CD4 counts is a risk factor for missing scheduled medical appointment. Patient with high CD4 counts on Anti-Retroviral Therapy their caregivers may have low risk perception which might affect adherence to scheduled medical appointment (Bigna et al., 2014) which later the trend of lower visit proportion increases risk of a CD4 counts decrease (Walburn et al., 2012), increased incidences of opportunistic infection (Sunguya et al., 2018.,) Mortality (Massavon et al., 2014). Study done by Massavon et al. (2014) found out that those children with low CD4 count are severely very ill and have higher chances of being admitted hence missing appointments. Additionally these might be patients who are defaulters or non-adhering to treatment or might have some social issues.

5.4 Children clinical factors associated with adherence to scheduled medical appointment among HIV infected children.

5.4.1 Children who had missed HIV treatment because drugs had finished

This study found that children who had never missed treatment because drugs had finished had decreased odds of missing scheduled clinic appointments as compared with children who had missed treatment because drugs had finished. This shows commitment of the caregivers to their children care to ensure their take drug as prescribed and this trigger them to attend all scheduled appointment so that they can have all drugs. Caregivers are encouraged to take their children to all scheduled medical appointment to refill their HIV drugs among other services. Similar findings by (Brenman *et al.*, 2010; MChugh *et al.*, 2017; Braitstein *et al.*, 2012), Who pointed out that children who failed to miss HIV drugs attended all scheduled medical appointment for refill of their HIV drugs among other services. Attending all clinic appointment is crucial in ensuring uptake of ART drugs (Van der Kop *et al.*, 2018; Makurumidze *et al.*, 2020).

5.4.2 Children who received HIV treatment in other health facility where they were unscheduled for medical appointment

Children who had not received HIV treatment in other health facility had decreased odds of missing scheduled clinic appointment as compared to those who received HIV care in other health facility, at 12months of follow up. The study result demonstrates that attending scheduled medical clinic regularly reduces chances of missing scheduled appointment as patients are monitored closely. Similar results were also reported by (Bastard et al, 2012). The caregivers who utilize more than one HIV clinic for services are likely to fail to adhere to scheduled medical appointments (Van der Kop et al., 2018). Study done by Van der Kop et al., (2018) pointed out that it is important for health care workers to encourage care givers to utilize regularly medical facility where they were scheduled for appointment.

5.4.3 Children CD4 counts

At 12 months of follow up there was an increasing trend for higher odds of missing scheduled medical appointments with an increase in CD4 counts. The higher the CD4 counts the lower the likelihood of adherence to scheduled medical appointments. This is consistent with findings from Braintstein *et al.* (2011), Horstman *et al.* (2010) that pointed out that having high CD4 counts is a risk factor of missing scheduled medical appointment.

5.4.4 Treatment for an opportunistic infection

This study found out that treatment of children for an opportunistic infection is not statistically associated with adherence to scheduled medical appointment at 12 months of follow up. Studies done by Horstman *et al.*, (2010) and Kerr *et al.*, (2012) pointed out that primary care giver may fail to attend their scheduled appointment for treatment of opportunistic infection for their children due to lack of means of transport, conflict with work demands, family illnesses and hospital admission and lack of partner support. HIV positive children with opportunistic infections are scheduled many medical appointment for follow up, this overburden caregivers

hence a risk factor to adherence to scheduled medical appointment {Wachira et al.,2012}.

5.5 Care givers perceptions associated with adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years receiving HIV care services at Kenyatta National Hospital, Kenya.

In the FGD caregivers perceived HIV care services provided to their children as being very beneficial to their health. The benefits influence the decision of the caregiver to adhere to scheduled medical appointment for example their live quality life so that we reduce death and development of opportunistic infection requiring frequent hospital admission. Similar finding were are noted by (Sunguya *et al.*, 2018; Massavon *et al.*, 2014; Brainstein *et al.*, 2011).

In this FGD care givers perceived the main factors that motivate adherence to scheduled medical appointment among their HIV infected children are; HIV care services provided to their HIV infected children such as HIV drug refilling, treatment of opportunistic infection. Caregiver taking short time in the medical clinic that provides the opportunity for them to return home or their work place to continue with their business. The Comprehensive Care Centre having friendly health care workers who understand care givers situation without stigmatizing and discrimination them. These factors need to be enhanced by health care workers, stakeholders and policy makes to improve on adherence to scheduled medical appointment among HIV infected children. Other Researchers have found out that following factors are associated with adherence to scheduled medical appointment among HIV infected children; HIV care services provided Schneiderman *et al.*,(2016), taking short time in the medical clinic while receiving HIV treatment (Ezekiel *et al.*, 2012). Having friendly health care workers who does not stigmatize patients. (Brainstein *etal.*, 2011).

In this FGD found out that care givers perceived some of the solution to promote adherence to scheduled medical appointments to include: Reducing the number of scheduled medical appointments, financial support to offset transport costs and Care providers focusing on HIV infected children with high CD4 counts.

5.6 Conclusions

- a) This study found adherence to scheduled HIV medical appointment among study participants to range from 75.6% to 81.9% at 6 and 12 months respectively. This different is affected by number of scheduled appointment, long waiting period in the medical clinic and financial constrain amd perceived stigma. Approximately 20% of children are at high risk of adverse effect associated with non-adherence to scheduled medical appointments.
- b) Adherence to scheduled medical appointments among study participants was associated with CD4 counts. The higher the CD4 counts the lower the likelihood of adherence to scheduled medical appointments.
- c) Children clinical factors associated with adherence to scheduled medical appointment at 12 months of follow up were, having low CD4 cell counts and receiving HIV treatment at the scheduled health facilities.
- d) Care givers perceived the main factors that motivate adherence to scheduled medical appointment among their HIV infected children are; HIV care services provided to their HIV infected children such as HIV drug refilling, treatment of opportunistic infection. Caregiver taking short time in the medical clinic and having friendly health care workers who understand care givers situation without stigmatizing and discrimination them.

5.7 Recommendations

- i. Adherence to attendance of scheduled medical appointment among children should be enhanced by HIV health care providers by reducing the number of scheduled medical appointments, Synchronizing appointments with school holidays for students, reducing waiting time in the Comprehensive Care Centre and financial support to offset transport costs and mitigating stigma.
- ii. Children with high CD4 counts should be targeted by Health care providers for individualized intervention to ensure they adhere to all scheduled medical appointments as they are at the high risk of missing appointment and hence fail to achieve benefits of HIV treatment.

- iii. Ministry of health and HIV policy makers to emphasize that all children to receive HIV treatment in the scheduled health facility by enhancing it in policies that deals with HIV prevention and differentiated care model for people living with HIV.
- iv. HIV care services provided to HIV infected children such as HIV drug refilling, treatment of opportunistic infection and Caregiver taking short time in the medical clinic and having friendly health care workers, non-stigmatizing staff, these are factors that need to be included in Policies on HIV prevention and treatment to enhance adherence to scheduled medical appointment among HIV infected children.

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APPENDICES

Appendix I: Informed Consent Explanation and Consent Form for SSQ

Introduction

My name is Peter Kirimi Mwiti a PhD student in the school of public health at JKUAT together with my colleagues we are conducting a project on determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years attending care in KNH, Kenya. There are low percentages of children aged 18 months to nine years who are adhering to regular attendance of scheduled medical appointment in HIV care services in Kenya. The researcher will ask you questions on HIV care services provided and you perception to them and factors motivating or hindering utilization of HIV care services among your children.

Purpose of the study

To establish determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years attending care in KNH, Kenya

Procedure

What to expect during the Interview

I will ask you simple questions on HIV care services and factors associated with adherence to HIV care among children.

If you choose not to participate or to leave the study

You have the choice to or not to participate in this research study. If you choose not to participate in this study or to leave the study during the interview process, you may do so freely without consequences against you.

Confidentiality of the records

Effort will be made to keep the information you provide confidential. You will be identified only by a code and personal information from the interview will not be released without your written permission. You will not be personally identified in any publication about this study. However absolute confidentiality cannot be guaranteed. Your records may be reviewed by the; Study Investigator or KNH/ UON Ethics Committee and JKUAT Committee.

Voluntariness

Being in the study is your choice

This consent form gives you information about the study, the risks and benefits, and the process that will be explained to you. Once you understand the study and if you agree to take part, you will be asked to sign your name or make your mark on this form. You will be given a copy to take home. Before you learn about the study, it is important that you know the following: Your participation in this study is entirely voluntary. You may decide to withdraw from the study at any time, without facing any consequences.

Risks and/or discomforts

We do not anticipate any risks or discomforts to you during this study. You will be requested to avail yourself for an interview at a place that you are most comfortable for a maximum of 30 minutes. You may feel uncomfortable to some extent when answering very sensitive question. You will have an option to decline to answer any question that you may feel uncomfortable with. We will make every effort to ensure comfort by protecting your privacy and confidentiality while you are participating in the study. The interview will take place in private place.

Benefits

There is no direct benefit to client. However the finding of the study will be beneficial to the relevant officers in motivating relevant program that will go a long way in enhancing adherence to scheduled medical appointment among children on

HIV care services.

Compensation

There is no cost to you for participating in this study.

Alternatives to participation

If you choose not to participate or to leave the study

You have the choice to or not to participate in this research study. If you choose not

to participate in this study or to leave the study during the interview process, you

may do so freely without consequences against you.

Principal investigator contact;

Obtaining additional information

If you ever have questions about this study contact: Principal Investigator, Peter

Kirimi Mwiti. Cell phone no: 0722959891 Email:mwitipk@yahoo.com or

pemwiti3@gmail.com

If you have any questions or concerns regarding the study and would like to talk to

someone other than the researcher, you are encouraged to contact the following:

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CONSENT FORM

Please read the information sheet above or have the information read to you carefully before completing and signing this consent form. If there are any questions you have about the study, please feel free to ask them to the investigator prior to signing your consent form.

Declaration of the volunteer

I Mr, Miss, Mrshereby give consent to participate in the proposed
study entitled;
To establish determinants of adherence to scheduled medical appointments among
HIV infected children aged 18 months to nine years attending care in KNH, Kenya. I

HIV infected children aged 18 months to nine years attending care in KNH, Kenya. I have read the information sheet concerning this study, I understand the purpose of the study and what will be required of me if I take part in the study. The risks and benefits if any have been explained to me. Any questions I have concerning the study have been adequately answered. I understand that at any time that I may wish to withdraw from this study I can do so without giving any reason and without affecting my access to normal health care and management. I realize that I will be interviewed. I consent voluntarily to participate in this study.

Subject's Name	
Signature or left thumb print	Date
Nam of the witness (Investigator)	Date
Signature (Sahihi)	

Appendix II: Consent Form for Focus Group Discussion

You will be contacted in order to carry out a group discussion for a study that aims;

To establish determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years attending care in KNH, Kenya.in order to devise interventions to improve adherence to scheduled medical appointment of children on HIV care. This study encourages your participation and collaboration that will lead to the development of strategies for intervention to improve adherence to regular medical care services among HIV infected children and thus improve their health outcome. Before commencement, you will be required to sign this consent form if you agree to participate.

Therefore please read the following carefully:

Participation

Your participation in the discussion will be totally voluntary. We will take all the necessary measures to maintain confidentiality, so that your name cannot be identified with what you have said. If, after reading this note, you decide that you do not wish to proceed with the interview, you can indicate this to the interviewer and the procedure will be discontinued. If you decide to go ahead, you should be aware that the interview data will be recorded on a computer for subsequent analysis without your name appearing at any moment. If you agree, please sign this consent form with a fictitious name that will be erased and changed into a number after the interview. The most important objective of the study that we will be carrying out is to help us understand; determinants of adherence to scheduled medical appointments among HIV infected children aged 18 months to nine years attending care in KNH, Kenya

We need to collect data about this subject in order to be able to design devise interventions to improve adherence to scheduled medical appointments of children on HIV care and improve their outcome The two groups will consists of each eight primary care giver of HIV infected children. The group discussion will be co-

ordinated by a member of the research team and will take about 45 minute of your

time. Not all members of the group will feel comfortable during the discussion, since

the topics to be discussed are sensitive. All participants will have equal right to

shares their views and will be respected. It is important for you to know that your

collaboration can help the development of strategies to improve adherence to

scheduled medical appointments of HIV infected children to HIV care and thus

improve their health. For any clarification you may contact any of the following

people:

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I agree to participate in the study and my fictitious name (pseudonym) is:
Date:
I certify that in my presence the participant will be informed about the possible
benefits and risks of participation in the research and the participant will be given

the opportunity to ask any questions.

Representativ	e of the research team:		
Nama/sign		Dota	
Name/ sign		Date	

Appendix III: Questionnaire Baseline

Study ID Date
Section One: Socio-Demographic Characteristics child/care giver
1). Sex of the care-giver (a) Male [] (b) Female []
2). Age of care-giver in years:
3) What is the care-givers current marital status?
a) Single (no partner) [] b) Married []
c) Divorced/separated [] d) Widow/widower [] e) No response[
4) What is your source of income?
a) Full time formal Employment [] b) Part time formal Employment []
c) Self-employed [] d) Unemployed []
5) What is your average monthly income?
(a) <5000 (b) 5001 -10000 (c) 10001-20000 (d) 20001 - 30000 (e) 30001-40000
(f) 40001 – 50000 g) 50001 – 60000 h)>60000
6) What is your highest level of education attained?
a) No formal education [] b) Primary level [] c) Secondary level []
d) University/college level []
7) What is the current age of your child under your care you have brought to clinic
today?(years)

8) Sex of the child
a) Male [] b) Female []
9) What is your relationship with the child you have brought to clinic today?
a) Parent: mother [] father [] b) Grandmother [] c) Grandfather [] d) Aunt []
e) Uncle [] f) Brother/Sister [] g) Other relative [] h) Foster care []
Section Two HIV care services; Clinician to confirm with file
10) How many children are under your care are on HIV care?
a) None [] b) 1 – 3 [] c) 4 and above []
11) What is the current WHO staging of your child?
a) Stage 1 or 2 b) stage 3 or 4
12) What is your child current CD4 count indicated in the file?
13) What is your child current viral load indicated in the file?
14) What are the HIV care services is your child getting?
a) Counseling [] b) psychosocial support [] c) Treatment of opportunistic infection []
d) ART treatment [] e) Nutritional supplementation [] f) Laboratory/ Radiological
Investigation [] g) Others
15) In your opinion, which HIV care services, do you think are more encouraging to your adherence to attendance to scheduled medical care appointment of your child?
a) Counseling [] b) psychosocial support []c) Treatment of opportunistic infection

d) ART treatment and drug refil [] e) Nutritional supplementation [] f) Laboratory/
Radiological Investigation [] g) Others
16 What are the factors that promote you in ensuring your child is adhering to attendance to regular scheduled medical care appointment at KNH?
a) Free drug [] b) Nutrition supplementation []
b) Counselling [] c) perceived benefit [] e) Others
17 What is your main challenge do you encounter in ensuring your child is adhering to regular scheduled medical care appointment on HIV care services at KNH?
 a) Different appointment schedule for child and care giver b) Long waiting time in the clinic c) Long distance [] d) Frequent clinic attendance [] e)Finance burden [] f) Family conflicts[] g) perceived stigma [] h) Male partner support []
i) Forgetfulness of the appointment date j) religious believe k) perception of child health
18) How long has your child been on HIV care at KNH?
a) Less than 1 year [] b) 2 years [] c) 3 years [] d) 4years [] e) 5 years and more []
19) How many medical HIV care clinic appointment have your child been scheduled for the last one year? a) None [] b) one [] c) two [] d) three[] e) four [] f) five and more []
20) How many medical scheduled HIV care clinic appointments have your child missed to attend on appointment date for the last one year? a) One [] b) two [] c) three [] d) four [] e) five or more [] f) None []
21) Do you receive any HIV care services? Yes [] No []

22) How is your relationship with your health care providers? a) Fair b) good c) very good

Section three Perceptions on HIV care services

- 23) How do you perceive HIV care services provided to your child? a)Time consuming
- b) No significant result expected since the child will not be healed
- c) Child has healed no need for continues clinic attendance
- d) Treatment is not better than traditional one and is very costly
- e) Very beneficial to the child health

Appendix IV: Focus Group Discussion

Venue	Date
Start time	End time
Focus group number and number of participant	
Name of moderator	
Name of rapporteur	
1. What are the benefit of HIV care services provid	ed to your child?
2 .What are the factors that motivate you to ensure	adherence to regular scheduled
medical appointment on HIV care services amon	ng HIV infected children?
3. On you own opinion, what are the major challenger	ges that you encounter when
taking your HIV infected child to scheduled m	nedical care appointment?
4. What are the ways of improving adherence to scl	heduled medical
appointment on HIV care services among HIV i	nfected children?
Thank you for cooperation	

Appendix V: Questionnaire Follows Up at 6 and 12 Months

Study ID Date of follow up at six months 12 month
Clinician to confirm with file
1) What is the current WHO staging of your child? a) Stage 1 or 2 b) stage 3 or 4
2) What is your child current CD4 count indicated in the file?
3) What is your child current viral load indicated in the file?
4) How many medical HIV care clinic appointment have your child been scheduled for the last six months?
a) None [] b) one [] c) two [] d) three [] e) four [] f) five and more []
5) How many medical scheduled HIV care clinic appointments have your child missed to attend on appointment date for the last six months? a)One [] b) two [] c) three [] d) four [] e) five or more [] f) None []
6) What HIV care services has your child received in the last six months?
a) Counseling [] b) psychosocial support [] c) Treatment of opportunistic infection [] d) ART treatment [] e) Nutritional supplementation [] f) Laboratory/ Radiological Investigation [] g) Others
7) How many times has your child been admitted to hospital for the last six months?
a) None b) one c) two d) three and above
8) What are the factors that promote you in ensuring your child is adhering to
attendance to regular scheduled medical care appointment at KNH?
a) Free drug []b) Nutrition supplimentation []b) Counselling []c) perceived benefit []e) Others

9) Has your child received HIV treatment in any other health facility in the last six
months? Yes [] No []
10) What is the main challenge you encountered in ensuring your child is adhering to
scheduled medical care appointment on HIV care services at KNH in the last six
months? a) Different appointment schedule for child and care giver b) Long waiting
time in the clinic c) Long distance [] d)Frequent clinic attendance [] e)
Finance burden [] f) Family conflicts[] g) Stigma perceived [] h) Male
partner support [] i) Forgetfulness of the appointment date j) religious believe k)
perception of the child is health.
11) Has your child missed HIV treatment in the last six months because the drugs
got finished? Yes [] No []
got imished. Test [140 []
12) Has your child been treated for any childhood illnesses other than HIV in the last
six months as an outpatient? Yes [] No []
If any and at any at the standard of the
If yes, what were they treated for?
13) What is your child's next scheduled return date of medical clinic appointment
indicated in the card? a) one month b) two months c) four months d) six month and
more
14) Do you receive any HIV care services? Yes [] No []
15) How is your relationship with your health care providers?
a) Fair b) good c) very good
THANK YOU

Appendix VI: Approvals



UNIVERSITY OF NAIROBI COLLEGE OF HEALTH SCIENCES P O BOX 19676 Code 00202 Telegrams: varsity Tel:(254-020) 2726300 Ext 44355



KNH-UON ERC
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Twitter: @UONKNH_ERC https://www.facebook.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL P O BOX 20723 Code 00202 Tel: 726300-9 Fax: 725272 Telegrams: MEDSUP, Nairobi

9th November 2016

Ref: KNH-ERC/A/442

Peter Kirimi Mwiti Principal Investigator College of Health Sciences J.K.U.A.T

Dear Peter

REVISED RESEARCH PROPOSAL – PREDICTORS OF RETENTION TO SCHEDULED MEDICAL APPOINTMENTS AMONG HIV INFECTED CHILDREN AGED 18 MONTHS TO NINE YEARS ATTENDING HIV CARE IN KENYATTA NATIONAL HOSPITAL, KENYA: A PROSPECTIVE COHORT STUDY (P688/09/2016)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above revised proposal. The approval period is from 9th November 2016- 8th November 2017.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (<u>Attach a comprehensive progress report to support the renewal</u>).
- f) Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- g) Submission of an <u>executive summary</u> report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

For more details consult the KNH- UoN ERC website http://www.erc.uonbi.ac.ke

Yours sincerely,

PROF. M.L. CHINDIA SECRETARY, KNH-UON ERC

The Principal, College of Health Sciences, UoN The Director CS, KNH

The Chairperson, KNH-UoN ERC



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15th November, 2017

12

Ref. No.KNH/ERC/R/155

Peter Kirimi Mwiti PhD Candidate College of Health Sciences J.K.U.A.T

Dear Peter,

Re: Approval of Annual Renewal – Study titled, "Predictors of retention to scheduled medical appointments among HIV infected children aged 18 months to nine years attending HIV care in Kenyatta National Hospital, Kenya; A prospective cohort study" (P688/09/2016)

Your communication dated 6th November, 2017 refers.

Upon review of the study progress report, the KNH-UoN ERC hereby grants extension of approval for ethical research protocol P688/09/2016.

The approval dates are 9^{th} November 2017 -8^{th} November 2018.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH- UoN ERC before implementation.
- c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH- UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal).
- f) Submission of an <u>executive summary</u> report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

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For more details consult the KNH- UoN ERC website http://www.erc.uonbi.ac.ke

Yours sincerely,

PROF. M.L. CHINDIA SECRETARY, KNH-UON ERC

The Principal, College of Health Sciences, UoN The Director CS, KNH

The Chairperson, KNH-UoN ERC



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KENYATTA NATIONAL HOSPITAL P O BOX 20723 Code 00202 Tel: 726300-9 Fax: 725272 Telegrams: MEDSUP, Nairobi

29th January, 2019

Ref. No.KNH/ERC/R/8

Peter Kirimi Mwiti PhD Candidate College of Health Sciences (CoHES) J.K.U.A.T

Dear Peter.

Re: Approval of Annual Renewal – Predictors of Retention to Scheduled Medical Appointments among HIV Infected Children Aged 18 Months to Nine Years Attending Care in KNH, Kenya; A Prospective Cohort Study (P688/09/2016)

Refer to your communication dated 15th January, 2019.

This is to acknowledge receipt of your study progress report and hereby grant you annual extension approval for ethics research protocol P688/09/2016 for data analysis only.

The approval dates are 9th November 2018 - 8th November 2019.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/JoN- ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal).
- f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- g) Submission of an <u>executive summary</u> report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

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For more details consult the KNH- UoN ERC website http://www.erc.uonbi.ac.ke

Yours sincerely,

PROF. M.L. CHINDIA SECRETARY, KNH-UON ERC

The Principal, College of Health Sciences, UoN The Director CS, KNH

The Chairperson, KNH-UoN ERC

Appendix VII: Publications

- 1. https://www.iosrjournals.org/iosr-jnhs/papers/vol9-issue1/Series-15/G0901155560.pdf
- 2. http://www.ijsrp.org/research-paper-0420.php?rp=P1009941
- 3. http://www.ijsred.com/volume4-issue5.html paper ID-V415P1