DECLARATION

I, Naikaali Irene Ssentongo , hereby declare that the contents of this research work are as a result of my findings and they have never been presented in any other University for an award

Signed.....Date.....

Supervisor Mrs. Okecho Florence

International Health Sciences University.

Signed…….Date……..

DEDICATION

This work is dedicated to my dear Parents Mr. and Mrs. Kitafuna Wilson for the sacrifice they made to lay a powerful foundation for my academic and personal life. To my dear husband Mr. Ssentongo Lawrence for the unconditional love and infinite support. My sons Benjamin Francis Kiggundu and Gerald Mathew Mugerwa who always remind me how pleasurable, honorable and regal it is to be a mummy.

ACKNOWLEDGEMENT

This piece of work is a result of the wonderful support team that provided me extra guidance during my time of study. Special thanks go to my Academic supervisor and mentor at the International Health Sciences University Mrs. Florence Okecho who directed this piece of work to its conclusion with patience and expertise.

Sincere appreciation to my Auntie Mrs. Nkata Joanita who offered to baby sit my sons while I dedicated more time to read and complete this piece of work. My dear Husband Mr. Ssentongo Lawrence for the never ending support, My dear friends who have always inspired me never to lose sight of my dream.

I sincerely acknowledge all the participants of this study. Special thanks to the mothers accessing HIV care and treatment at Kamwokya Christian caring community. I acknowledge the support I received from the executive director Mr. Mbazira Francis.

Lastly to all the potential readers of this thesis, It's my hope that we shall together use the findings and recommendations in this study to improve the utilisation of paediatric HIV services in Uganda

TABLE OF CONTENT

LIST OF FIGURES AND TABLES

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
HIV	Human Immune virus
IMF	International Monetary Fund
ICW	International Community of Women Living with HIV/AIDS
KCCC	Kamwokya Christian Caring Community
MOH	Ministry of Health
NPC	National Paediatric Conference
PEPFAR	Presidential Emergency Plan for AIDS Relief
UBOS	Uganda Bureau of Statistics
UHSBS	Uganda HIV/AIDS Sero-Behavioural Survey
UNAIDS	United Nation Programme on HIV/AIDS
USAID	United States Agency for International Development
WHO	World Health Organization

ABSTRACT

Background: While adult utilisation of HIV services is increasing in Uganda, the utilisation of similar services by children is still lagging behind. It is reported that only 3 out of 10 HIV positive children in Uganda are able to receive the HIV care services they need to survive childhood. This study examined factors influencing the utilisation of paediatric HIV services by known HIV positive mothers at Kamwokya Christian Caring Community (KCCC) to be able to facilitate the designing of appropriate and effective interventions that will facilitate the scale up of paediatric HIV service utilization at KCCC and Kampala district at large.

Methodology: A cross sectional survey was conducted among 320 HIV positive mothers aged 15 years and above accessing HIV services at KCCC. Semi structured questionnaires and a focused interview guide were used to collect data after obtaining written consent. Data was entered and analyzed in Epi data and SPSS soft ware. Univariate, Bivariate and Multivariate analysis was done to identify factors influencing the utilisation of Paediatric HIV services by the HIV positive mothers.

Results: At bivariate analysis, the study revealed the following factors having a significant relationship with utilization of paediatric HIV services by the HIV positive mothers; Marital status, duration in marriage, Knowledge of signs and symptoms of HIV in children, awareness about availability of free HIV services for children, disclosure of child's HIV status, discrimination by family members and power relations in a home. Further analysis at multivariate level identified only the awareness about the availability of free HIV services for children as the single factor independently predicting utilisation of paediatric HIV services by the HIV positive mothers OR 11.95 95% (2.38-50.46).

Conclusion: Continued sensitization of parents about availability of free HIV services for children together with deliberate efforts to link mothers to HIV service points for children are essential measures in scaling up utilisation of HIV services for children in Uganda

Operational Definitions

Adult: An adult is any person aged 15 years and above receiving HIV/AIDS care and support services.

Counseling: Counseling is described as a process of guiding someone to understand his or her problem, support on identifying possible options, prioritizing and finally being able to make an informed decision. This is usually achieved through face to face interaction with the person who has the problem and a person who is offering help.

Children: A young person aged 0-14 years infected or affected by HIV/AIDS

HIV Services: HIV services considered under this study include HIV counseling, testing, Septrin prophylaxis, treatment of opportunistic Infections, Anti-Retroviral Therapy, nutritional support, psychosocial support among others. However HIV testing was used as a proxy indicator for utilisation of HIV services for children by the HIV positive mothers.

HIV positive mother: A woman positively diagnosed with HIV, having children aged 0-14 years either biological or non-biological in her care and is receiving HIV services from Kamwokya Christian Caring Community

Paediatric: Children aged 0-14years old receiving HIV/AIDS services.

PCR Test**: A special HIV blood test done on infants to test for the presence of HIV**

CHAPTER 1

INTRODUCTION

The study aimed at establishing the factors that influence the utilisation of paediatric HIV services by the HIV positive mothers already receiving HIV care and treatment. It was conceptualised that the utilisation of paediatric HIV services by the HIV positive mothers who are already accessing similar services for themselves is influenced by maternal factors, environmental factors and facility factors. The introduction is presented in the following sections: The back ground provides a brief of the HIV/AIDS epidemic globally, regionally and locally. The current response to the epidemic, a justification of the urgency of the problem and the rationale of the study. The section also includes the statement of the problem, the justification for the study, research objectives and questions and the conceptual framework

1.0: Back ground to the study

HIV/AIDS epidemic

The Human Immune virus (HIV), the virus that causes Acquired Immunodeficiency Syndrome (AIDS), has become one of the world's most serious health and development challenges. More than 1.8 million people have died of AIDS worldwide, and another 34 million are currently living with HIV/AIDS. Of the 34 million, living with HIV/AIDS, 3.4 million are children less than 15 years (UNAIDS, 2011).

Majority of the children living with HIV/AIDS in the world almost 9 in 10 live in sub-Saharan Africa. HIV and AIDS is a major cause of infant and childhood mortality and morbidity in Africa. In many of the African countries where HIV prevalence is above 5 percent, child

mortality rates have not fallen in line with global trends. This is most probably due to the high risk of mortality associated with untreated HIV infections in young children (AVERT, 2009).

The prevalence in Uganda currently is estimated at 7.3 % for Adults and 0.7% in children. There are approximately 1.2 million people infected with HIV of which about 140,000 are children below 15 years of age. Of the 100,000 new infections in 2009/2010, 20,000 of them were in children occurring as a result of mother to child transmission (MOH, 2010). This is the most significant shortcoming in the response to paediatric HIV where inadequate prevention of mother to child transmission allows a large number of children to be born with HIV inspite of it being largely preventable.

Research studies have continued to report that almost half of pregnant women in Uganda deliver from home and have never taken an HIV test. This implies that many of the children born to these mothers are undiagnosed with HIV making it difficult for them to access the necessary HIV services (USAID, HCI project, 2012).

Response to HIV/AIDS

While adult utilisation of HIV services in Uganda is on the increase as a result of increased awareness and access to free medication, the number of children accessing HIVAIDS testing services is lagging behind. Of the 42,000 children eligible for enrollment on Antiretroviral Therapy (ART), only 41% had started ART in 2009 (MOH, 2010). Uganda on average has about 100 general Hospitals, 166 Health center IVs and 905 Health Centre III. Out of all these Health facilities only 68% of the general Hospitals and 58% of the health center IVs provide some form of Paediatric HIV care and treatment service compared to 100% and 82% respectively providing adult HIV services(NPC ,2010). This contributes to only 8.3% paediatric on ART in

Uganda the factors associated with the slow progress in the utilisation of paediatric HIV services in Uganda especially among parents who are also HIV positive and accessing adult HIV services are unclear. This study therefore seeks to establish the factors influencing utilization of paediatric HIV services among HIV positive mothers in Uganda using a case study of Kamwokya Christian Caring community. The findings will be useful in informing the design of appropriate and effective interventions to that will facilitate the scale up of paediatric HIV service utilisation in Uganda.

1.2. Statement of the problem

In Uganda while adult utilisation of HIV services is increasing throughout the country, the utilisation of similar services by children is still lagging behind (MOH, 2010). According to the new WHO guidelines, it is recommended that children start treatment as early as possible after diagnosis and suggest that where necessary they receive a complex set of drugs including protease inhibitors to reduce the likelihood of drug resistance. Children differ from adults in that they have high rates of viral replication, very high HIV-1 viral load, high rate of CD4 cell destruction and faster rate of disease progression yet good immunological response to ART.

In Uganda however; reports indicate a slow progress towards the WHO recommendation. It is reported that only 3 out of 10 HIV positive children in Uganda are able to receive the treatment they need (MOH, 2010). Usually children living with HIV have already weakened immune systems which render them more prone to common childhood infections which last longer and don't respond well to treatment. The media especially the national newspaper attributed this lag to the reluctance of parents to enrol their children for the HIV services (New vision, 2011).

1.3. Main Objective

To examine the factors influencing the utilisation of paediatric HIV/AIDS services by HIV positive mothers in Kampala.

1.4 Specific Objectives

To determine the proportion of HIV positive mothers at KCCC who have accessed paediatric HIV services for their children aged 0-14 years in the past 3years.

To examine the maternal factors influencing the utilization of paediatric HIV services among 371 HIV positive mothers accessing HIV services from KCCC in the past 3 years.

To examine the Environmental factors influencing the utilisation of paediatric HIV services by 371 HIV positive mothers accessing HIV services from KCCC in the past 3 years.

To examine the facility factors influencing the utilisation of paediatric HIV services among 371 HIV positive mothers accessing HIV services from KCCC in the past 3 year.

1.5 Research questions

What is the proportion of HIV positive mothers who have accessed Paediatric HIV services for their children?

What are the Maternal factors influencing the utilisation of paediatric HIV services by HIV positive mothers?

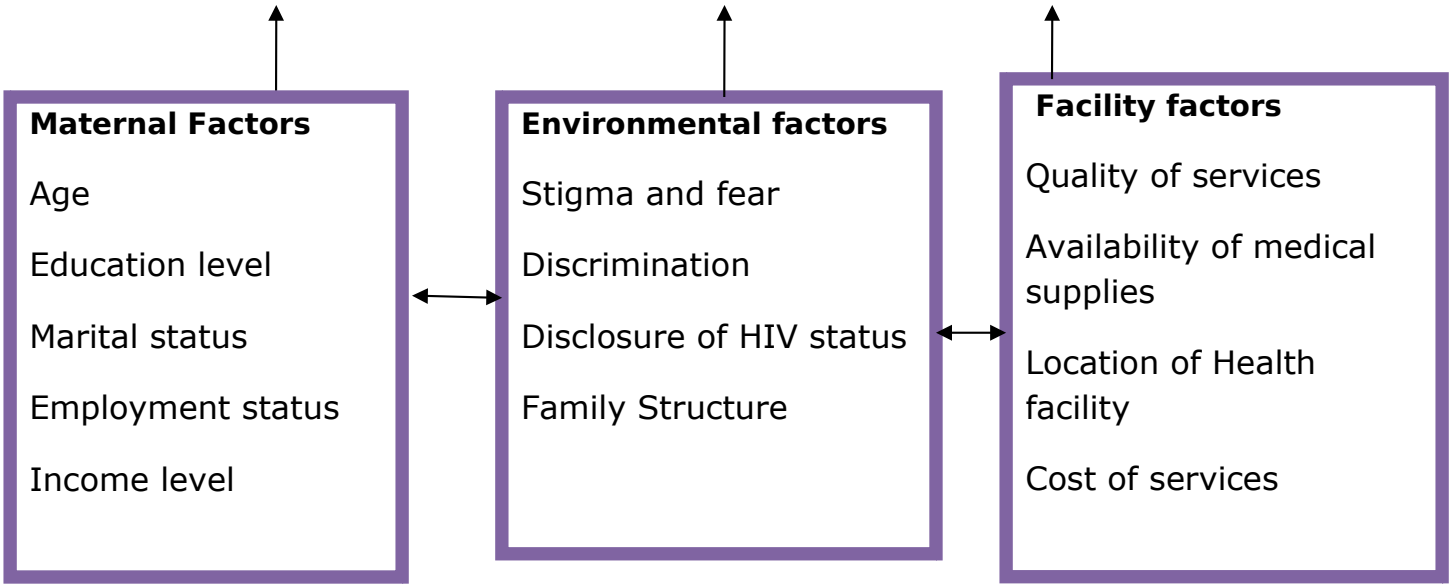
What are the environmental factors influencing the utilisation of paediatric HIV services by HIV positive mothers?

What are the facility factors influencing the utilisation of paediatric HIV services by HIV positive mothers?

1.3 Significance of the study

Studies conducted in the area of utilisation of HIV/AIDS services for children have not adequately addressed the factors associated with the utilisation of HIV paediatric services by parents specifically the HIV positive mothers who themselves are accessing similar services. Information generated from this study will be used by the researcher, KCCC and other stakeholders to facilitate designing of appropriate and effective interventions to facilitate the scale up of Paediatric HIV service utilization in Uganda. This will in return contribute positively to the decrease in childhood morbidity and mortality thus leading to improved quality of life, reduction in the burden of paediatric HIV/AIDS and pressures on the health system and economic development.

1.7 Conceptual framework



The conceptual framework above, was derived from the assumption that the utilisation of paediatric HIV services by HIV positive mothers who are already accessing HIV care and treatment services was dependent on a number of factors categorized into; maternal factors ie those factors that characterize an individual and can be used to differentiate one individual from another such as the mother's age, education level, marital status, employment status, income level. Environmental factors which refer to those larger scale forces within society that affect the thoughts, feelings and behaviors of individuals towards the utilisation of HIV services for children. Such as, stigma and fear, discrimination, disclosure of HIV status, family structure. Lastly facility factors associated with provision of HIV/AIDS care and treatment services at the health facility. These include availability of medical supplies, location of health facility, waiting time, and cost for services.

CHAPTER 2

LITERATURE REVIEW

Introduction

This literature was built on past studies conducted in Uganda and other countries in the area of paediatric HIV and AIDS treatment, care and support. Literature was reviewed systematically as

per the study objectives to analyze the contributions of various researchers in the area of paediatric HIV services and the barriers to the utilisation of such services.

2.1. Utilisation of Paediatric HIV services

It is estimated that about 390,000 children younger than 15 years were infected with HIV in 2010, mostly through mother-to-child transmission during pregnancy, delivery, or breastfeeding. Effective prevention services, including prenatal HIV testing, prenatal antiretroviral (ARV) prophylaxis, and safe alternatives to breastfeeding, are offered to fewer than 10% of pregnant women worldwide. Because of this global failure in prevention of HIV in children, by the end of 2010 an estimated 3.4 million children were living with HIV infection globally; of these children, 9 out of 10 reside in sub-Saharan Africa (American Academy of paediatrics, 2007).

Although there have been great improvements in the prevention of Paediatric HIV infections and provision of ART for children with HIV infection in the more developed nations, many barriers remain to scaling up HIV prevention and treatment for children in resource limited settings of the world. One of the major barriers sighted is that related to HIV diagnostic testing which means that many infants and young children will die before HIV is diagnosed or therapy given. This is further worsened by the psychological barriers to testing infants. The stigma of the diagnosis for the mother and the child and lack of treatment availability may keep women from testing themselves and testing their children for HIV (American Academy of Paediatrics, 2007)

In a retrospective observational cohort study conducted in Malawi to assess the continuity of care and outcome of paediatric HIV prevention, testing and treatment services, it was reported that out of 14,669 pregnant women who had received HIV counseling and testing services from major hospitals in the country and turned out HIV positive, only 7875 babies born to these mothers had received a DNA PCR HIV test. Of the 7875 babies that had been tested, 13.8%

(1084) turned HIV positive and only 320 were enrolled for HIV treatment. This trend shows a huge gap that many African countries are facing in terms of scaling up paediatric HIV care and treatment. The study goes ahead to report that even out of the 320 who were enrolled 34.2% of them died. These findings further support the need for a more detailed study to analyse the factors that are still holding back many parents from accessing HIV services for their children despite the availability of such services in many health facilities in different African countries.

Research and clinical reports continue to reveal that many HIV infected children particularly those younger than 13 years don't know they are HIV infected owing to parental concerns about the impact of the disclosure on their mental health. However, related studies have gone ahead to disapprove these parental fears towards disclosure claiming not direct association between disclosure and mental health of the children infected. In a cohort study conducted by Harlem hospital and Columbia University to examine patterns of HIV status disclosure to 77 prenatally HIV infected ethnic minority children aged between 3 to 13 years and explore the association between knowledge of HIV status and emotional behavioral outcomes. It was revealed child knowledge of HIV status was not closely associated with mental health problems instead there was a statistical trend for children who knew their HIV status to be less depressed than children who did not know (Claude et al,2002). The study also revealed that greater social disclosure to other family members was found when the child had an AIDS diagnosis as well as when the care giver was negative and not the child's biological parent. There need for further studies to understand factors that hinder biological parents from disclosing HIV status to children which is a key success factor in HIV service provision.

In Kenya a study was conducted to assess the barriers to utilisation of paediatric HIV treatment and care among caregivers in the community, it was found out that while 40 percent of adults

who need HIV treatment are receiving it, only 11percent of the eligible children are on this life saving therapy. Out of the 1,180 respondents surveyed, 27% reported having no knowledge about any symptom of HIV in children.

2.2 Maternal Factors

In the study carried out in Kenya on the barriers to utilisation of paediatric HIV services, participants revealed a degree of knowledge about HIV which was expressed in their willingness to accept an HIV positive child in their home and in school together with the HIV negative children. This indicated a promising trend upon which programs can build on to enhance the social support networks required to increase Utilisation of HIV services among children. However in South Africa a similar study also revealed that many children are being infected with HIV after birth and yet too few are entering care through early diagnosis. This trend was attributed to poor education and support for women in their infant feeding choices.

In a cross sectional study conducted in Khartoum- Sudan at one of the antenatal Clinics called Faith Elrahmam Elbashir to investigate pregnant women's basic knowledge and attitude towards HIV and Mother to Child Transmission, it was revealed that among the participants interviewed age, education level and religion played an important role in the knowledge levels as well as attitude towards utilisation of HIV services out of the 1005 participants, 79% had good knowledge about HIV and Mother to child transmission and these were mainly Women aged 26 years and above with at least secondary level education and practicing Muslims faith had better knowledge about HIV and were more willing to go for Voluntary counseling and testing (Mariam M. Mohamed et al ,2007). Further research is needed to examine whether these factors also influence parental contribution to the utilisation of paediatric HIV services.

A cross sectional survey conducted in Malawi indicated that age of the patient significantly had an influence on their access to antiretroviral therapy. The young adults found it more difficult to access services. The age disparities were even more pronounced when comparing adults with children. The study noted that it was important for HIV/AIDS programs to take age into consideration to avoid age disparity in the utilisation of treatment service(Muula et al,2008)

Similarly A retrospective study conducted in 11 United States health facilities indicated that age was a significant facilitator or barrier to the utilisation of HIV care and treatment. The findings of the study clearly indicated that older patients tend to utilise services more than the younger patients. This study however used retrospective data by reviewing the patient files and analysing variables of age and utilisation in form of number of visits and hospitalization. The study though noted a disparity in utilisation amongst minority groups it did not analyse other social demographic factors other than age in the study (Fleishman, 2005).

Income levels coupled with cost are considered major barriers to access of HIV/AIDS services. According to the results of the Uganda National household survey conducted in 2009/2010, the average income of male headed households was UGX 336,900 which was higher than that of female headed households UGX 226,300(UBOS2009/2010). These low levels of income have a direct effect on the expenditure pattern as well as household priorities especially when it comes to Health care needs of the family members.

In a study carried out in Kenya, cost was identified as a major barrier to utilisation of HIV /AIDS services. The study revealed that although the Kenyan government provides free Antiretroviral Therapy, clients bear additional costs including transport, consultation fees and medication to treat opportunistic infections. This in return defers caregivers from accessing services for

themselves as well as their children. It is most likely similar challenges might affect utilisation of HIV services even in Uganda.

In a cross sectional study conducted in Ethiopia, it was reported that there was a significant difference in the workload of women living in HIV affected households who may themselves be HIV positive as compared to their counterparts in non HIV affected households. On average it was reported that women in HIV affected households spent between 11.4 to 11.6 hours a week in the gardens while those in non HIV infected households spent close to 33.6 hours a week in the gardens (Lori, 2000).

Unemployment has been sighted as one of the major factors affecting parents living with HIV. In a book by the International Monetary fund, it is highlighted that HIV/AIDS tends to generally affect all households through its macro-economic effects such as changes in wages. (IMF, 2004) It is also important to remember that many families in sub-Saharan Africa are already living in poverty, poor infrastructure and limited access to basic care services even prior to HIV infection. (Geoff et al, 2000). As a result of HIV the economic burden is aggravated leading to parents prioritizing the already constrained resources into medical care for the parent infected with HIV. In the process children living in such poverty stricken families see their living standards fall as household incomes decline and expenditure redirected. This means children are usually caught at the cross roads and in the process end up having their health and psychological needs coming secondary to that of their parents.

Still related to the above report by the International monetary fund, a study conducted in Cape Town South Africa to assess the challenges faced by PLWHA, it was reported from the focused group discussions of women infected with HIV that amidst unemployment, poverty and lower

social economic status, HIV becomes secondary to PLWHA. The findings further revealed that AIDS was only one of the social stressors threatening people living in every day poverty. In the South African study, this still applies as respondents in the study meant to assess women's feelings, attitudes and experience on learning their HIV status during pregnancy revealed that avoiding social and economic risks was more important than the possibility of support or other gains through disclosure. These fears towards disclosure are most likely related to utilisation of HIV services by both the mothers and their children.

2.1 Facility Factors

According to a cross sectional study conducted in Kenya by Councils' Horizons to examine community awareness about paediatric HIV care and treatment and the barriers to caregiver seeking HIV services for their HIV infected children, it was reported that facility factors too played an active role in hindering the utilisation of HIV services by caregivers for their children. The factors that came out strongly included the lack of properly trained health personnel to handle children in care and inadequate supply of medicines and equipment. A similar study conducted in South Africa by the Infectious Disease Society of America to establish the challenges to Paediatric ART reported similar findings. For example in one of the health facilities surveyed in Gauteng, there were limited human resources with inadequate paediatric clinical skills, other health facilities within the region lacked physicians and primary health care nurses were not trained to handle children with HIV (Tammy et al, 2006). To further express this skills gap among health workers, the Kenya study on the barriers to the utilisation of paediatric HIV services quoted one of the health workers saying that they were not counsellors yet they were expected to be aware with no relevant information. Another reported that as health workers, they usually find it hard to disclose to the child their HIV status on their own. They usually

encourage the parents to do so who equally lack the relevant skills on how to break such information (Kiragu et al, 2007).

The American Academy of Paediatric further elaborates on the issue of lack of clinicians to provide HIV care to children. It is reported that even with appropriate HIV diagnostic testing and availability of drugs for treatment of HIV infection and prophylaxis for HIV associated infections, a lack of personnel trained in treatment of children with HIV severely limits access to treatment for large numbers of children. The report further stresses that in many areas of the world, medical care is provided by physicians, nurses and other clinicians with training and experience in the management of adults but not children. This situation clearly relates to the Ugandan situation where reports from the 4th National Paediatric conference indicated that despite having countable paediatricians in Uganda, many of them have limited skills to identify and treat HIV positive children.

A prospective cohort study conducted in British Columbia targeting the drug user's population established that patient's utilisation of HIV/AIDS treatment services was influenced by the level of experience of the physicians in the facilities. Patients were less willing to utilise services in cases where the physicians were less experienced in treating HIV positive patients. The study noted that patients that saw physicians who were least experienced were 5 times less likely to utilise HIV/AIDS services than those that saw experienced physicians. The study therefore emphasized that the health workers level of experience is a determinant in the patient's decision to utilise the services. The study however as noted above was carried out in the drug user population and not in the ordinary adult population leaving a gap to be determined by further studies. The study was carried out in Britain and the findings may not be generalisable to other geographical areas such as Uganda and further still the findings of the population studied may

not be generalized to other populations since the study was specifically carried out on drug users who may have unique characteristics that may differ from the other populations especially the target population under this particular study.

Assuming that appropriate HIV diagnostic testing is available and the necessary clinical personnel are available to provide care and treatment to HIV-infected children, appropriate formulations of ARV reagents for children is also necessary. Lack of availability of appropriate ARV formulations that are inexpensive and easily usable is a major impediment to access to economical health care for children with HIV. For example, liquid drug formulations often require special storage such as refrigeration. The large volume of liquid formulations dispensed to allow ART to continue uninterrupted between clinic visits may make use of such drugs difficult in settings where storage are a challenge especially for mothers in rural areas who may lack refrigeration facilities. Still related to the paediatric regements, a qualitative study conducted in selected hospitals in Addis Ababa in 2008 to explore the barriers and facilitators to antiretroviral medication adherence among HIV- Infected paediatric patients, it was revealed that over-dosage(heavily pill burden) was one of the major factors leading to non adherence to treatment. Caregivers felt that the drugs given to children were too many and this tended to discourage many from adhering to their children's treatment (Biadqiliqn et al 2008)

Stressing further the contribution of facility factors to the low utilisation of paediatric HIV services in South Africa, it was noted that the integration of ART with other primary health care services has been very limited hindering effective scale up of paediatric care for HIV. The functional and structural separation of these services interferes with continuity of care for children and results in high leakage rates between the component services and numerous missed appointments and loss to follow up. In other instances, many health facilities separate HIV

services for children and adults by clinic days or even location with limited attention given to a family based approach to HIV care. Furthermore Quality of education given to caregivers concerning HIV services for children is also reported as a contributory factor to utilisation of HIV services for children. A qualitative study conducted in Addis Ababa Ethiopia in six selected hospitals revealed that despite efforts being made by the hospital staff to sensitize patients about HIV treatment and adherence, caregiver still express a lack of knowledge on the actual benefit of taking the medication

In a study conducted by Horizons in Kenya to assess the barriers to Paediatric HIV testing and care results from the key informant interviews reported that distance and quality of services were major hindrances to proper utilisation of paediatric HIV services. One of the health workers interviewed reported that people in the area where very poor, some of them have to walk several kilometres all the way and then sit and queue for long hours before receiving services for their children. They then walk back very tired, hungry and pathetic. Generally as a quality of service barrier, the study revealed that the main reason why care givers expressed dissatisfaction was because of drugs inadequacies (57%) and Waiting time (43%).

Distance is one major factor that has been reported as one of the determinates for health seeking behavior. In a report by USAID, it is noted that bad roads, the cost of transport and wages foregone as a result of having to travel distances to the health facility make it cheaper for a villager to seek treatment from traditional health practitioners who may otherwise have very limited knowledge and skills in handling specific health conditions (HPI, 2009). Further research into the issue of distance is needed to understand why despite the similar distances to be covered the number of adults up taking services for themselves is higher compared to that of their children.

2.2. Environmental factors

HIV related stigma and fear are still pervasive in many local communities in Uganda and many other developing countries. In an exploratory study conducted in Cape Town South Africa, it was reported that People Living with HIV/AIDS found it difficult to disclose their HIV status for fear of being rejected and discriminated against. It was concluded that AIDS related stigma remains one of the barriers to curb the further spread of the disease amongst people who are aware of their HIV positive status and therefore a major challenge to the efficacy of risk reduction interventions for PLWHA and other risk groups. (Allanise et al, 2010). Still related to stigma and discrimination, the results from the focused group discussion with the HIV positive African women, revealed that there several myth surrounding the spread of among communities were still posing a big challenge to the struggle against HIV in Africa. Many people still regard HIV as a punishment to God for the promiscuous especially for women, gay or black and this in return deters HIV positive women from seeking HIV services. This finding reveals a likely close association between this finding and the utilisation of HIV services by children born of HIV positive mothers.

In a cross-sectional study conducted in the Middle East and North Africa region (MENA) women were found to be unwilling to complain to their husbands if they are unwell, fearing that their husbands would subsequently divorce them and find another wife. Women, generally, did not discuss these kinds of problems with female friends and relatives, fearing that the information would reach others (Remien et al, 2010).

In a study conducted in Kenya among households to identify barriers to utilisation of paediatric services, it was found that social cultural influence had an effect on the health seeking behaviors of adults which in turn influences utilisation of health services for their children. Adults

preferred traditional healers to modern medical personnel because of confidentiality and accessibility issues (Horizon 2006). The study further revealed that stigma and fear hinder parents from taking their children for HIV services. This is because the communities continue to blame parents for infecting their children and also associate their HIV positive status to immorality. This fear in return hinders parents from accessing HIV services for themselves as well as their children.

In a cross-sectional study conducted in the Middle East and North Africa region (MENA), it was noted that social cultural factors play a significant role in both males and female use of HIV/AIDS care and treatment. Stigma due to the social and cultural factors affects women differently from males (Remien et al, 2010). In addition, the stigma associated with HIV infection, work or family responsibilities, homophobia, and masculine responses to health and disease may make it more difficult for one to seek care and treatment let alone seeking health services including HIV services for their children.

Still related to stigma and lack of information, evidence available indicates that either exclusive breast feeding or exclusive feeding with milk alternatives rather than mixed feeding is effective in reducing mother to child transmission of HIV. However HIV positive mothers rarely receive correct information about feeding options and alternatives to milk. In addition decisions to breast feed are often based in HIV related stigma associated with women who don't breast feed and cultural ideas concerning what behavior constitutes proper motherhood. This implies that even mothers who are already aware of the potential risks associated with breast feeding may fear that not breastfeeding their babies may provoke negative comments among neighbors (ICW, 2008).

In a report presented during the 4th National HIV Paediatric conference in Uganda, it was reported that due to the feeling that after all children living with HIV are at risk of dying , so many caregivers and health workers deny children living with HIV a right to health care. This study seeks to find out as to whether even the HIV positive mothers who are already accessing HIV services for themselves also harbor similar feelings towards their children.

Disclosure issues are key to the access and utilisation of HIV services by both adults and children infected with HIV. Usually decisions about HIV disclosure are dependents on perceived AIDS- related stigma. In the South African based study on challenges faced by People living HIV and AIDS focused group participants expressed fears of disclosure that might lead to rejection by their families or partners or losing their jobs. One of the women interviewed reported that the day she tried to disclosure her status to her family members, they suggested buying her gloves to wear whenever she prepared their meals better still to even move out of their house to avoid infecting them (Allanise et al,2010). This demonstrates the imagined danger, which the person living with HIV poses to the rest of the family and also most likely to affect utilisation of HIV services by the children in such families.

Juliet Tembe (2010) identifies gender inequality as one of the key factors escalating the spread of HIV/AIDS as well as worsening the impact of HIV. In an assessment report on the Utilisation of HIV/AIDS testing in Thailand it was reported that among HIV infected adults, the gender differences partly explain the reason why men generally seek HIV services much latter than women. Further research is needed to relate these gender differences and the effect they have on utilisation of HIV services by the children. Furthermore gender based violence is highlighted in many studies as one of the potential risk factors for women accessing HIV service. Women are generally disempowered and usually have no choice as to what happens with their own sexual

and sexual patterns. There is a complex link between gender power relations, intimate partner violence, drug use and HIV/AIDS. Human rights watch reports from Zambia confirm that gender based human rights abuses are in fact very real barriers to accessing and adhering to treatment. The report further stresses that although the Zambian government has taken some steps to address violence and discrimination against women, generally major gaps remain in legislation, HIV treatment programs and support services to poverty among women living with HIV (Human Rights Watch, 2007).

In a cross sectional study conducted in United States of America to examine the effects of family structure on children's access to health care, it was revealed that generally children from single father families were more likely to have poor access to health care compared to those from both parents' families. On the contrary children from single mother families were more than likely to have equal or slightly more access to health care compared to those in two parents family (Lindsay et al, 2006). In the context of HIV affected families, further investigation is needed to establish whether similar results can still apply for families in which either one or both parents are living with HIV/AIDS and the reasons for this occurrence.

In a cross sectional study conducted in South Africa on the factors influencing utilisation of HIV services among children (AIDS Care 2010), it was reported that maternal guilt and fear of negative consequences resulting from disclosure of HIV positive results to the children were a major hindrance to utilisation of HIV services among children. Reports from the International Community of women living with HIV/AIDS also report that many HIV positive mothers experience extreme psychological stress over what will happen to their children if they themselves die. They also worry about the health and wellbeing of their children in addition to having feelings of anxiety about disclosing to children either their own positive status or the

positive status of the child. These factors seem to have a close association with the utilisation of HIV services for the children by these mothers.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This section includes details on the study design, study population, sample size calculation, sampling procedures, sources of data, study variables, data collection techniques, data collection tools, plans for data analysis, quality control issues, ethical issues, budget and work plan.

3.2 Study design

The study took the form of a cross sectional survey design. This was because the study aimed at collecting data at a single point in time and the measurement of the independent and dependent variables was to be done at the same time. Secondly being an academic research, there were restriction on the timeframe in which the study had to be completed. The study design allowed

for a mix of both quantitative and qualitative approaches to ensure data triangulation for validity and completeness. Quantitative data was obtained using the semi structured questionnaires while qualitative data was obtained from the focused group interviews. Cross sectional studies are often used as a basis for health policy planning and it's upon this background that the findings and recommendations are used towards improvement in the utilisation of paediatric HIV services in Kampala district and Uganda at large.

3.2 Study Setting

The study was conducted at Kamwokya Christian Caring Community (KCCC) one of the major health facilities located in Kamwokya parish II, Kampala central Division. Kamwokya II has a total of 10 zones with a total population of about 15,735 people (Uganda Census 2002). It is a slummy area housing the urban poor. The 10 zones within Kamwokya II parish include church area, Kisenyi1 and II, Kifumbira I and II, central zone, coutaafrica, mawanda, green valley and market area.

KCCC was founded in 1987 through Voluntary efforts of the members of the small Christian communities as a care and treatment project for persons living with HIV/AIDS. These were mainly the poor, vulnerable and marginalized people including women, commercial sex workers, widows, youth, elderly and disabled persons. Latter in 2004, with support from the presidential Emergency fund for AIDS Relief (PEPFAR), the facility started providing free Antiretroviral therapy to clients already in their care as well as those that came to the facility to be tested. Comprehensive HIV services for children were started in 2009. According to the 2010 annual report, KCCC had total of 9411 adult's clients in HIV care of which 5634 were parents/caregivers in active HIV care. The total number of children in HIV care was only 288 of which only 59 were receiving ART. The facility is well stocked with drugs, and treatment

services for people infected with HIV/AIDS offered free of charge. However some of the HIV positive parents/care takers are reluctant to bring their children for HIV/AIDS services leading to low utilisation of paediatric HIV services at this facility.

3.3 Study Population:

3.3.1 Target Population

The larger population to which the study was generalised included all HIV positive adult parents/ caregivers 15 years and above in Kampala district were already accessing and utilising HIV/AIDS care and treatment services in various health facilities ~~in Kampala at the time of the~~ study.

3.3.2 Accessible population

The accessible population included all the adult HIV positive clients 15 years and above, both male and female accessing HIV care and treatment services from Kamwokya Christian caring community for the past 3years or from the time paediatric HIV services were introduced at the facility.

3.3.3 Sample

The study sample included only the HIV positive females aged 15 years and above, accessing HIV care and treatment service from Kamwokya Christian caring community for the past 3 years and have children (ages 0-14) under their care.

3.4 Sample size determination

The sample size was determined using Leslie Kish formula as illustrated below

$$n = \frac{z^2.p.q}{d^2}$$

Where:

n = the required sample size

z = value corresponding to the 95% confidence interval for a standard normal distribution curve = 1.96

p = Estimated proportion of HIV positive children in Uganda on Anti-Retroviral treatment (ART) [Number of children on ART =0.41(MOH, 2010)]

q =1-p

d = maximum acceptable sampling error = 0.05

$n = \frac{1.96^2 x 0.41 x 0.0.59}{0.05^2} =$ 371 respondents (HIV positive mothers)

3.5 Selection Criteria

Inclusion: All HIV positive mothers aged 15years and above with children aged between 0-14 years of age, and are receiving HIV care and treatment services from Kamwokya Christian caring Community.

Exclusion: Out of the selected study sample, all those mothers who declined to participate in the study, those that were very ill as well as those that were mentally impaired were excluded from the study.

3.6 Sampling techniques

Step 1: Purposive sampling

Using the client appointment register and with the help of the counselor, lists of all HIV positive mothers on appointment within the 12.5 days of data collection were obtained from the clinic (Purposive sampling).

Step 2: Simple Random sampling (Lottery method)

For the semi structured interview

On average KCCC books about 80 adult clients on appointment per day at its clinic. Out of these 80 approximately 70% are women. Therefore using the appointment lists for the respective days with in the interview period, each mother's name was assigned a number which was written on a separate piece of white paper, folded and then placed in a tin. The tin was then covered and shaken to ensure that all the pieces evenly mixed. This ensured that each piece of paper had an equal chance of being selected. Latter, a piece of paper was picked at random to be included in the sample and this exercise of shaking and picking was repeated until a total of 30 names had been randomly selected from the tin to be interviewed on each day with the last day of the interview having only 11 participants. This made a total of 371 respondents for the semi structured questionnaires. The interview was conducted in 12.5days

For the Focused group interviews

From the appointment register, 20 mothers were randomly selected from the list using a similar method to form audience for the focused group discussions. These mothers were divided into 2 groups of 10 each to participate in the interviews on the same day and time. The researcher was assisted by the trained research assistants to facilitate the interviews.

3.7 Study variables

Dependent Variables: The dependent variable was the Utilisation of paediatric HIV/AIDS services (0-14years). These were defined by a series of questions grouped together to clearly explain the problem.

- Independent Variables**:** The independent variables were the factors influencing the utilisation of paediatric HIV services by the HIV positive mothers. These included maternal factors (age, sex, marital status, religion, educational levels) , Environmental factors (Stigma and fear, discrimination, disclosure of HIV status, family structure) and facility factors(quality of services, location of health facility, availability of medical supplies and cost of services)

3.8 Data collection methods

Using interview method of data collection, data on each of the 3 specific objectives was collected by a team of research assistants supervised by the researcher using a semi structured standardised questionnaire. The questionnaire had mainly closed and a few open ended questions for easy categorisation

In addition the researcher conducted 2 focus group discussions involving a total of 20 HIV positive mothers receiving HIV care at KCCC. The participants in the focus group interviews were randomly selected from the appointment register excluding those that had already participated in the semi structured questionnaire interviews.

Data collection tools

Interviewer administered semi-structured questionnaires containing both closed ended and open ended questions were used to collect data relevant to the research. Both the questionnaire and the focused group interview guide contained questions on both the dependent variable and

independent variables. The focused interview guide also asks questions on key recommendations from the respondents on how to increase the utilisation of paediatrics HIV services by the HIV positive mothers.

Data management.

Quantitative data: The questionnaires were reviewed at the end of each day of data collection to ensure completeness of entries. Latter codes were developed to facilitate electronic data entries using Epi data and latter export to SPSS software for analysis.

Qualitative data: Data from the open ended questions was reviewed separately at the end of each day to establish merging themes and latter data coded.

3.9 Data analysis

Quantitative data

Quantitative data related to each of the strategic objectives was analysed majorly at three different stages: Univariate, Bivariate and Multivariate

Univariate analysis

For the dependent variable, the proportion of HIV positive mothers who had utilised HIV services for their children was determined. Frequencies were run for each of the independent

variables explaining utilisation of HIV services. Data was presented using bar charts and frequency tables.

Bivariate analysis

At this level, the relationship between the utilisation of paediatric HIV services and the different factors influencing the utilisation of paediatric HIV services by the HIV positive mothers was analysed. Cross tabulations were used to establish the relationship between the dependent and independent variables. The strength of association was determined using the chi-square test.

Multivariate Analysis

At this level, logistic regression was done to determine which of the factors among the (Maternal, environmental and facility) were associated with the probability of occurrence of an HIV positive mother up taking paediatric HIV services for their children. The most significant variables were determined as those with P value less than 0.005.

Qualitative data

Field notes from the focused group discussions were reviewed and edited at the end of each day to describe the views and opinions of the respondents. Analysis was done manually. Merging themes were identified and described in line with the objectives of the study.

3.10 Quality control techniques

The questionnaire was designed in simple English to enable the research assistance ably translate the questions directly from English to Luganda. The research assistants were selected on the basis of their knowledge of English and Luganda. They were given a 2 days training to enable them understand the study and ably adminster the tool.

Latter the trained research assistants participated in the pretesting of the tool. The tool was pretested among 10 respondents who were also HIV positive mothers accessing HIV services from Nsambya Home care an HIV department of Nsambya Hospital. Nsambya Home care was chosen on the basis of having similar characteristic with the study area.

Validity testing of the tool was also done by a panel of 10 experts. The experts were holders of a master's degree in social sciences or a health related field. They had prior experience in research and specifically in designing, administering and testing of questionnaires.

3.11 Ethical consideration

Approval to conduct the study was sought from the Uganda national council of science and technology through International Health Sciences University Research and Ethical Committee. Permission to conduct the study at KCCC health center was sought from the in-charges of health center. Participation in the study was voluntary and in addition effort was made to clearly explain the objectives of the study to the participants to enable them have a clear understanding of the purpose and the benefit of the study. This was followed by the signing of the informed consent form.

Strict confidentiality was maintained all through data collection and analysis by use of anonymous identifiers and access to the data collected was restricted to the researcher.

3.12 Study limitations

The study was conducted at KCCC in Kamwokya Parish, Kampala central division. This being a faith based Non-governmental organization and not a major health care treatment facility,

findings from this study may not be generalized to other bigger Health care facilities such as hospitals.

Out of the estimated sample of 371 respondents, only 320 respondents were able to participate in the study within the given timeframe

CHAPTER 4

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1. Introduction

This chapter presents analyses and interprets data of the study titled: Factors influencing the utilisation of Paediatric HIV services among HIV positive mothers. A case study of Kamwokya Christian caring community in Kampala Central Division. The study population were the HIV positive mothers aged 15 years and above accessing HIV care and treatment services from Kamwokya Christian caring community. The total number of respondents was 320 females. Data was analysed in line with the study variables. Univariate analysis, Bivariate and Multivariate analysis was done to establish the factors influencing the utilisation of Paediatric HIV services by the HIV positive mothers.

Univariate analysis of Factors influencing the utilisation of Paediatric HIV services among 320 HIV pregnant women accessing HIV services at Kamwokya Christian Caring Community.

Maternal Characteristics

A total of 320 mothers were interviewed with a mean age of 38years. Majority of the mothers had primary level education 136 (42.5%), 116 (36.3%) were Catholics by religious denomination and were residing within the urban setting 240 (87.5%). A big number of mothers were in a cohabiting relationship 79(26.7%), 67(20.9%) widowed, 65(20.3%) separated, 55(17.2%) single was only 54(16.9%) were legally married. For those who indicated that they were legally married or cohabiting, 204 (63.7%) said they had been in the relationship for over 6months. Considering the employment status of the mother, majority were self employed 178(55.6%) while more than half of them said that they earn a monthly income of less than 150,000/= 196 (67.8%). Looking at the number of children the respondents had under their care, more than half of the mothers said they had 3 or more children 216(67.5) while 104(32.5%) said they had 2 or less. Table 1 below summarises the maternal factors considered to influence utilisation of paediatric HIV services by HIV positive mothers.

Table 1: Maternal characteristics of 320 mothers accessing HIV services at KCCC, Kampala

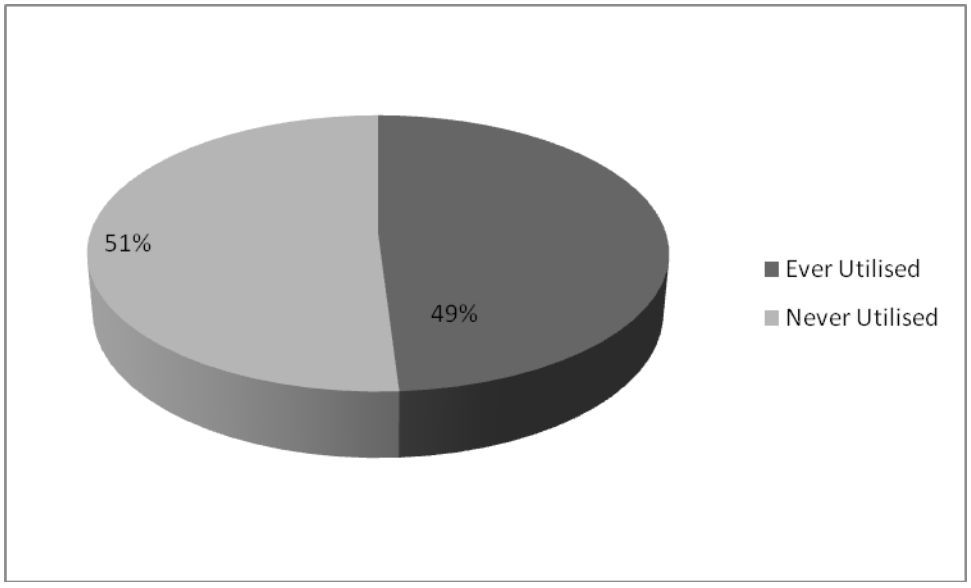
Variable	N (%)	Utilised service N (%)	Never utilised service N (%)
Age			
≤38 years	173 (54.1)	96 (58.9)	77 (49.0)
≥39 years	147 (45.9)	67 (41.1)	80 (51.0)
Education level			
None	36 (11.2)	18 (11.0)	18 (11.5)
Primary	136 (42.5)	66 (40.5)	70 (44.6)
O level	106 (33.1)	57 (35.0)	49 (31.2)
A level	25 (7.8)	12 (07.0)	13 (08.3)
Tertiary	17 (5.3)	10 (06.1)	7 (04.5)
Religion			
Catholic	116 (36.3)	56 (34.4)	60 (38.2)
Protestant	90 (28.1)	46 (28.2)	44 (28.0)
Muslim	53 (16.6)	30 (18.4)	23 (14.6)
Pentecostal	18 (5.6)	09 (05.5)	09 (05.7)
Adventist	42 (13.1)	21 (12.9)	21 (13.4)
Others	1 (0.3)	01 (00.6)	0 (00.0)
Residence			
Urban	240 (87.5)	147 (90.2)	133 (84.7)
Rural	40 (12.5)	16 (09.8)	24 (15.3)
Marital status			
Single	55 (17.2)	20 (12.3)	35 (22.3)
Married	54 (16.9)	39 (23.9)	15 (09.6)
Cohabiting	79 (26.7)	45 (27.6)	34 (21.9)
Separated	65 (20.3)	29 (17.8)	36 (22.9)
Widowed	67 (20.9)	30 (18.4)	37 (23.7)
Duration in marriage			
<6 months	116 (36.3)	77 (47.2)	39 (24.8)
≥6 months	204 (63.7)	86 (52.8)	118 (75.8)
Employment status			
Self employed	178 (55.6)	86 (52.8)	92 (58.6)
Formal employment	70 (21.9)	38(23.3)	32 (20.4)

Unemployed	68 (21.2)	37 (22.7)	31 (19.7)
Others	4 (1.3)	02 (01.2)	02 (01.3)
Income per month			
≤150,000	196 (67.8)	97 (65.5)	99 (70.2)
>150,000	93 (32.2)	51 (34.5)	42 (29.8)
Parity (0-14 years)			
<2 children	104 (32.5)	44 (27.0)	60 (38.2)
≥3 children	216 (67.5)	119 (73.0)	97 (61.8)

Utilisation of Paediatric HIV services

HIV testing was used as a proxy indicator for utilisation of paediatric HIV services by the HIV positive mothers accessing services from KCCC. The study revealed that about 163 (51%) of the mothers had never utilised HIV testing services for their children compared to 147(49%) who had ever utilised HIV testing services as illustrated in the chart below.

Figure1: Showing Utilisation of HIV testing services by 320 HIV positive mothers accessing HIV services from KCCC, Kampala



One interesting finding from one of the focus group discussion conducted revealed that mothers had limited knowledge on the importance of HIV treatment thus the low utilisation of Paediatric HIV services as indicated below;

…… We don't understand the actual benefit of HIV treatment, here once you are found HIV positive they ask you to enroll for care and treatment. They emphasise adherence to the drugs without explaining to us how the drugs will help us live longer. With the little knowledge and burden of taking pills all your life, one wouldn't think about their children going through the same pain.

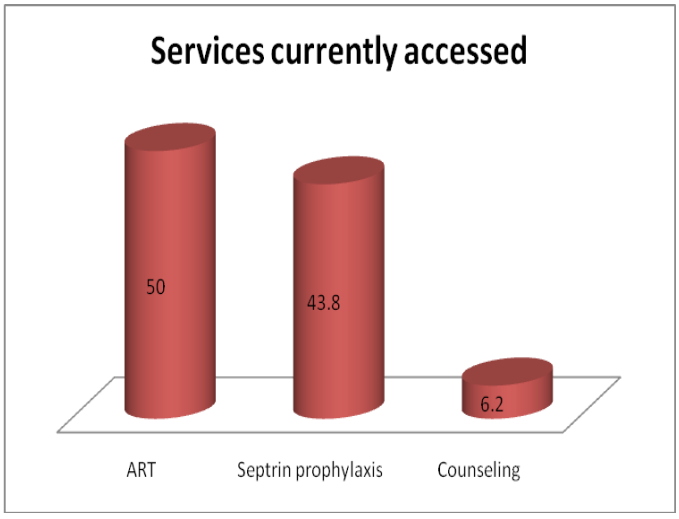
It is important to also note that mothers aged 38 years and below were reported having utilised HIV testing services for their children more 96(58.9%) compared to those aged 39 years and above. Surprisingly there was no much difference in the level of utilisation of HIV testing services among mothers in relation to level of education. Looking at religion as a factor influencing utilisation of paediatric HIV services, the study reported that despite majority of respondents being Catholics and accessing HIV services from KCCC a Catholics founded institution, more than half of the mothers who are Catholics had not utilised HIV services for their children 60 (38.2%). Looking at Marital status in relation with utilisation of HIV testing services for the children, the study revealed that about 37(23.7%) of the mothers who were widowed had never utilised HIV testing services for their children while 45 (27.6%) of the cohabiting mothers had ever utilised the service. Considering duration in marriage, mothers who

had stayed in a relationship longer than 6 months had utilised HIV testing services for their children 118(75.8%) compared to their counterparts who had stayed in a relationship less than 6months.

HIV Services being accessed

Of the 163 mothers who had ever utilised HIV testing services for their children, Only 32 reported accessing HIV services beyond HIV testing. The services being accessed included Antiretroviral Therapy 16(50%), Septrin prophylaxis and other opportunistic Infection treatment 14(43.8%) and only 3(6.2%) reported receiving HIV counselling services as illustrated in the graph below.

Figure 2: Showing HIV services currently being accessed by the HIV positive mothers for their children.



Bivariate analysis of Maternal factors influencing utilisation of paediatric HIV services.

Cross tabulations together were used to determine the relationship between the utilisation of paediatric HIV services and the maternal factors influencing the utilisation of paediatric HIV

services by the mothers. Latter the strength of association was determined using the chi-square test. In reference to table 2 below; the findings revealed that, single mothers were 0.95 times less likely to access HIV testing services for their children compared to their counterparts who were married, cohabiting or widowed or separated (OR=0.95, 95% CI=(0.81-1.11). Duration in marriage was also seen to have a significant relationship with the utilisation of HIV services by the HIV positive mother. Mothers who have been in a relationship (married/ cohabiting) longer than 6months were 4.28 times more likely to utilise HIV services for their children compared to those in a relationship of less than 6months.(OR= 4.28, 95% CI=(1.12-16.35)). Knowledge of HIV symptoms in children was another significant factor seen to be associated with the utilisation of HIV services by the mothers where by those who knew at least some two HIV symptoms in children were 3 times more likely to access HIV services compared to those who did not know. Awareness of availability of free HIV services in health facilities and hospitals in the country was also seen to have a significant relationship with the utilisation of services, Mothers who were aware were 4.8 times more likely to access services compared those who didn't P-value 0.001.

Table2: Bivariate analysis of Maternal factors influencing utilisation of paediatric HIV services.

Variable	N (%)	OR (95%CI)	P-value
Age			
≤38 years	173 (54.1)	0.67 (0.43-1.04)	0.070
≥39 years	147 (45.9)		
Education level			
None	36 (42.5)	1.08 (0.86-1.35)	0.882
Primary	136 (33.1)		
O level	106 (11.3)		
A level	25 (7.8)		
Tertiary	17 (5.3)		
Religion			
Catholic	116 (36.3)	1.04 (0.88-1.22)	0.850
Protestant	90 (28.1)		
Muslim	53 (16.6)		
Pentecostal	18 (5.6)		
Adventist	42 (13.1)		
Others	1 (0.3)		
Residence			
Urban	240 (87.5)	1.66 (0.84-3.26)	0.139
Rural	40 (12.5)		
Marital status			
Single	55 (17.2)	0.95 (0.81-1.11)	0.001
Married	54 (16.9)		
Cohabiting	79 (26.7)		
Separated	65 (20.3)		
Widowed	67 (20.9)		
Duration in marriage			
<6 months	116 (36.3)		
≥6 months	204 (63.7)	4.28 (1.12-16.35)	<0.001
Employment status			
Self employed	178 (55.6)		
Formal employment	70 (21.9)	1.01 (0.74-1.38)	0.650
Unemployed	68 (21.2)		
Others	4 (1.3)		
Income per month			
≤150,000	196 (67.8)		
>150,000	93 (32.2)	1.24 (0.75-2.03)	0.395
Parity (0-14 years)			
<2 children	104 (32.5)		
≥3 children	216 (67.5)	1.67 (1.04-2.68)	0.032
Knowledge of Symptoms			
Yes	172 (53.7)		
No	148 (46.3)	3.01 (1.91-4.75)	<0.001
Awareness of free HIV care			
Yes	253 (79.1)		
No	67 (20.9)	4.89 (2.61-9.14)	<0.001

Environmental factors influencing utilisation of paediatric HIV services.

A descriptive analysis of the environmental factors seen to influence HIV positive mothers utilisation of paediatric HIV services revealed that more than half 204(63.8%) were self employed self employed, 254(84.6%) said their family members would not discriminate against their HIV positive child, 271(84.7%) acknowledged that failure to disclose to any family member that their child was HIV positive hinders access to HIV services, 245(76.6%) did not belong to any social support group while more than half 182(56.9%) said they were the main decision makers in their home and 285(89.1%) said they would disclose to a family member about the HIV positive status of their child as seen in Table 3 below.

The focus group discussion further expounded on the issue of disclosure where by 8 out of 10 mothers reported that;

.....Once people know that you have lost your husband to HIV, they automatically start pointing fingers towards your last born children implying that they too are infected and will not survive long. So this fear to confirm the community's suspicion over one's child often discourages us from disclosing and also seeking HIV services.

Bivariate analysis of Environmental factors influencing utilisation o paediatric HIV services.

Further analysis of the relationship between environmental factors and the utilisation of paediatric HIV services to establish the level of significance revealed that mothers who said they would be discriminated against by their family for having an HIV positive child were 0.5 times

less likely to utilise HIV services for their children compared to those who said they wouldn't (OR 0.55, 95% CI= (0.37-0.84)). Mothers who disagreed that failure to disclose to a family member about their HIV positive status of their child would affect their utilisation of HIV services were 0.56 times less likely utilise HIV services for their children (OR 0.56, 95% CI= (0.38-0.82)). Lastly mothers who said they were the main decision makers in their home were 2.54 times more likely to utilise HIV services for their children (OR 2.54, 95% CI= (1.56-4.14)) as illustrated in table 3 below.

Table3: Bivariate analysis of Environmental factors influencing utilisation of Paediatric HIV services by HIV positive mothers.

Variable	N (%)	Utilised service	Never utilised service	OR (95%CI)	P-value
Occupation of HHH					
Formally employed	82 (25.6)	18 (41.9)	64 (23.1)	1.83 (1.04-3.23)	0.035
Self-employed	204 (63.8)	21 (48.8)	183 (66.1)		
Unemployed	34 (10.6)	4 (9.3)	30 (10.8)		
Discrimination by family					
No	254 (84.6)	30 (69.8)	224 (88.1)		
Yes	12 (4.0)	4 (9.3)	8 (2.9)	0.55 (0.37-0.84)	0.005
I don't know	34 (11.3)	9 (20.9)	25 (9.0)		
Failure to disclose to family hinders access to service					
Yes	271 (84.7)	29 (67.4)	242 (87.4)		
No	49 (15.3)	14 (32.6)	35 (12.6)	0.56 (0.38-0.82)	0.002
Belong to social support group					
Yes	75 (23.4)	4 (9.3)	71 (25.6)		
No	245 (76.6)	39 (90.7)	206 (74.4)	0.29 (0.10-0.86)	0.025
Decision maker in at home					
Partner	112 (35.0)	74 (45.4)	38 (24.2)	1	
Self	182 (56.9)	79 (48.5)	103(65.6)	2.54 (1.56-4.14)	<0.001
Relative	26 (8.1)	10 (6.1)	16 (10.2)	3.46 (1.40-8.56)	0.007
Would you disclose to family HIV status of child					
Yes	285 (89.1)	152 (93.3)	133 (84.7)	2.39 (1.12-5.09)	0.024
No	35 (10.9)	11 (6.7)	23 (15.3)		

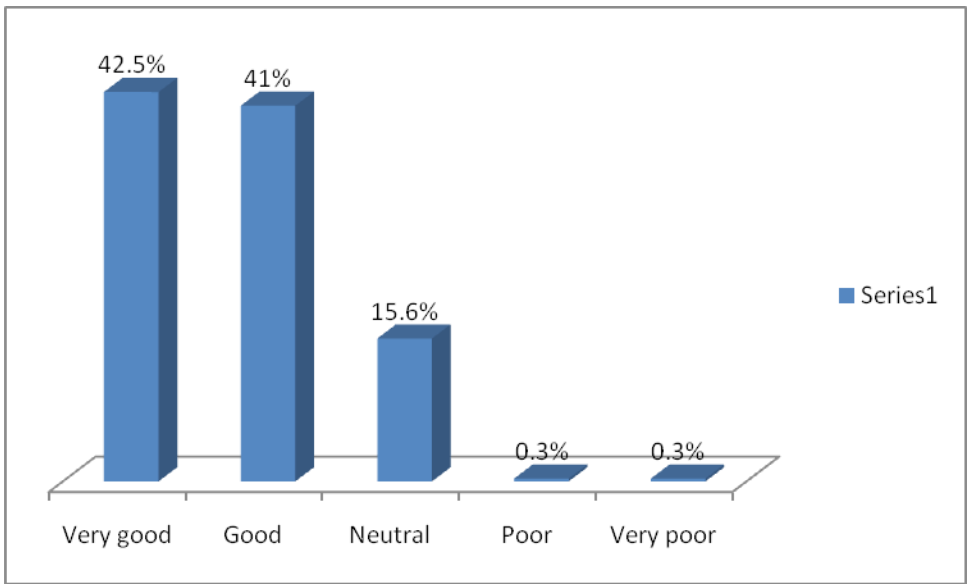
Facility factors influencing utilisation of paediatric HIV services by the HIV positive mothers.

Among the facility factors considered to influence utilisation of paediatric HIV services by the HIV positive mothers as illustrated in Figure 2 below included the following; quality of service where by majority of the respondents said that the quality of HIV services provided at KCCC was very good 136(42.5%), while more than half of respondents were actually not aware that HIV services for children were available at the facility 173(54.1). When asked about the usability of HIV drugs as well as storage, majority of the respondents expressed a lack of knowledge 147(56.5%) and 206(64.4%) respectively. However for those who said the drugs were difficult to use, some of the reasons given for this response included a lack of refrigeration facilities to store the syrups as well as the consistency in drug administration. The issue of consistency was further expounded by the mothers, who participated in the focused group discussion as summarised below,

....the drugs need to be administered at specific times without fail and yet we have to go and work. Sometimes we delay to return home and find the children already asleep.

When asked about the issue of waiting time and whether it would affect a mothers' decision to utilise HIV services for their children, majority of the respondents disagreed that waiting time could actually have an influence on the mother's decision 140(43.8%).

Figure 3: Showing the rating of quality of HIV services at KCCC



The results from one of the focused group discussions conducted further expounded on the issue of waiting time. 8 out of 10 Mothers agreed that waiting time could actually affect a mother's decision to utilise HIV services. Some of the reasons given are summarised below,

.....The clinic starts operating at 9.00am yet clients are already at the reception area by 6.30am. That means that usually the first client leaves at about 10.00am yet we have to be at work and also our kids at school. This discourages many parents who end up missing out on their kids' medical appointments.

.....The number of health workers especially doctors at KCCC is small compared to the number of clients. There are only 2 doctors and this increases on the time spent waiting for

services. The longer mothers stay waiting for services, the more discouraged they get to bring their kids to receive HIV services.

A number of mothers also reported residing more than 3miles away from KCCC health facility while 249(77.8) confirmed that there were additional costs incurred in utilising paediatric HIV services at KCCC.

Bivariant Analysis of health facility Factors influencing utilisation of paediatric HIV services by the HIV positive mothers at KCCC.

The results of this study did not show any significant relationship between facility factors and utilisation of HIV services by the HIV positive mothers. As seen in table 4 below.

Table 4. Bivariate analysis of Health facility factors influencing utilisation of Paediatric HIV services by the HIV positive mothers.

Variable	N (%)	Utilised service	Never utilised service	OR (95%CI)	P-value
Quality of service					
Very good	136 (42.5)	22 (55)	114 (40.7)	1	
Good	132 (41.3)	15 (37.5)	117 (41.8)	0.91 (0.57-1.48)	0.713
Neutral	50 (15.6)	3 (7.5)	47 (16.8)	0.76 (0.39-1.46)	0.416
Poor	1 (0.3)	0 (0.0)	1 (0.3)	1.57	1.00
Very poor	1 (0.3)	0 (0.0)	1 (0.3)	1.57	1.00
Availability of service					
Yes	143 (44.6)	17 (42.5)	126 (45.0)	1	
No	4 (1.3)	1 (2.5)	3 (1.1)	1.98 (0.27-14.49)	0.501
I don't know	173 (54.1)	22 (55.0)	151 (53.9)	3.21 (2.02-5.09)	<0.001
HIV drugs are easy to use					
Yes	105 (40.4)	12 (30.0)	93 (33.2)	1	
No	8 (3.1)	2 (5.0)	6 (2.1)	3.77 (0.87-16.30)	0.075
I don't know	147 (56.5)	26 (65)	121 (64.6)	6.50 (3.76-11.25)	<0.001
Easy to store drugs					
Yes	107 (33.4)	13 (32.5)	94 (33.6)	1	
No	7 (2.2)	0 (0.00)	7 (2.5)	1.13 (0.21-6.15)	0.889
I don't know	206 (64.4)	0 (0.00)	179 (63.9)	4.54 (2.71-7.59)	<0.001
Waiting time is long	119 (37.2)	12 (30.0)	107 (38.2)	1	
Agree	140 (43.8)	20 (50.0)	120 (42.9)	1.17 (0.72-1.91)	0.530
Disagree	61 (19.0)	8 (20.0)	53 (18.9)	1.52 (0.82-2.82)	0.189
Neutral					
Distance from health facility	116 (36.2)	60 (36.8)	56 (35.7)	1	
<1 mile	87 (27.2)	41 (25.2)	46 (29.3)	1.20 (0.69-2.10)	0.517
1 to 3 miles	117 (36.6)	62 (38.0)	55 (35.0)	0.95 (0.57-1.59)	0.846
>3 miles	71(22.2)	7 (17.5)	64 (22.9)	1	
	249 (77.8)	33 (82.5)	216 (77.1)	1.13 (0.64-1.98)	0.675
Costs incurred					
Yes					
No					

Multivariate analysis of factors associated with utilisation of paediatric HIV services by the HIV positive mothers.

At multivariate analysis level, the key factor that had shown a significant relationship with utilisation of paediatric HIV services by the HIV positive mother were run in a logistic regression model to determine which of the factors were more likely to predict utilisation of paediatric HIV services by the mothers. Awareness of free HIV care services for children p-value 0.001 (OR 11.95, 95% CI= (2.83-50.46)) presented as the most likely predictor of utilisation of Paediatric HIV services by the HIV positive mothers. As illustrated in table 5 below.

Table5: Multivariate analysis of factors associated with utilisation of paediatric HIV services by the HIV positive Mothers.

Variables	OR (95%CI)	P-value
Awareness of free HIV care		
Yes	11.95 (2.83-50.46)	0.001
No	1	
Would you disclose to family member child's status	45.76 (2.78-754.39)	0.007
Yes	1	
No		
Do you agree not disclosing Hinders access to care	1	
	0.06 (0.006-0.626)	0.018
Yes		
No		

CHAPTER 5

DISCUSSION

Results of this study must be interpreted in line with its limited setting. The study was conducted in Kamwokya in Kampala central division and specifically on HIV positive mothers accessing HIV care and treatment services from Kamwokya Christian Caring Community.

Utilisation of Paediatric HIV services

Half of the respondents in this study had never utilised HIV services for their children. This low level of utilisation directly points to the fact that many mothers actually are not even aware of the HIV status of their children. This lack of awareness impacts on the quality of life of the children in the sense that they are denied access to vital services that would help in prolonging their lives. This result agrees with the Uganda Ministry of health reports that in 2009, only 41% of HIV positive children in Uganda had accessed HIV treatment (MOH, 2010). This trend of low uptake of paediatric HIV services is not only unique for Uganda but Kenya as well. In Kenya, while 40% of eligible adults are already on HIV treatment, only 11% of the eligible children are lucky enough to receive this life saving treatment (Karusa Kiragu et al, 2007).

Denial to access of HIV services by children is closely linked to the high mortality rate of fewer than five in many sub-Saharan countries in Africa. A qualitative study conducted in South Africa confirmed that many parents will only decide to take an HIV test for their children after recurrent illness and at the point when the child's health is deteriorating (Yeap et al, 2010). Usually at this point the child's immunity has gone so low to respond effectively to the strong HIV medication

sometimes leading to more complicated side effects including death. To further support the issue of early diagnosis and treatment, a retrospective cohort study conducted in Malawi reported that the survival rate of infants initiated early on Anti retroviral therapy was seven times higher than those who are not initiated on HIV treatment (Braun et al, 2011).

5.1. Maternal Factors

This current study revealed that awareness of availability of free HIV services for children was closely associated with utilisation of HIV services for children by the HIV positive mothers. Meaning that if an HIV positive mother is aware of the availability of free HIV services for her children then her likelihood of utilising these services for her children are 4 times higher than those who actually weren't aware. This is true given the fact that Knowledge is a crucial factor in decision making. However we also note from this same study that despite mothers being aware of the free services almost half of them still had actually not utilised HIV testing services for their children. This means that probably other factors such as fear of negative repercussions, low incomes, facility related factors come into play to influence mothers' decisions to finally utilise these services for their children.

The above finding also agrees with findings from an empirical study of the relationship between situation awareness and decision making conducted among a group of 24 military men in Southern Australia. A strong relationship was found between situation awareness and decision making where by participant's with a high degree of situation awareness made high quality decisions compared to their counterparts with less awareness. However, the findings from this study also agreed that high decision making could not entirely be attributed to situation awareness but rather other factors also play a key role.

Surprisingly, there was not much difference in the utilisation of Paediatric HIV services by mothers in relation to their levels of education. Ideally education levels should be a key factor towards the quality of decisions an individual makes. However we also know that when it comes to issues of health, this assumption seizes to stand. Many educated people have been reported as having very poor health seeking behaviours. They usually fail to translate their knowledge into practice possibly because of fears. With the advent of e-health, many educated people have access to internet services that provides them access to health information. This wide access to health information sometimes exposes them to confusing information that they can not easily understand as non medical people. In the process they even fear to seek medical attention for fear of confirming their suspicions. This partly contributes to late presentation of patients for HIV treatment.

To elaborate further other studies have actually reported education levels having a direct link to utilisation of HIV /AIDS treatment services. For example a cross sectional study that was conducted among African Americans established that there was a significant relationship between participant's education and the use of HIV/AIDS treatment (Kalichman et al, 1999). However when you are to compare the study subjects in this study and that of Kalichman et al, the former was looking at utilisation of services by the mothers for their children while the latter looked at utilisation of HIV services for the study subjects themselves. And also considering the quality as well as the educational levels of people in United States and that of Uganda, there is a huge difference which may partly explain this difference in findings.

Marital status of the mother was a very significant factor in determining utilisation of HIV services by the HIV positive mothers. Single mothers were less likely to utilise HIV services for their children compared to the married or cohabiting mothers. This probably is related to support

factors where by single mothers may lack the moral and financial support needed to raise a family and at the same time attend to her own needs as an HIV positive person as well as those of her children . On the other hand it is assumed that mothers living with their partners tend to have some degree of moral and financial support from their partners that may allow them to pay attention to the HIV care needs of their children. The study also showed a significant relationship between the period of time a mother has stayed in the relationship and their utilisation of paediatric HIV services. Mothers who had stayed in a relationship longer than 6 months were more 4 times likely to utilise HIV services for their children compared to those that had stayed in shorter than 6 months. One possible reason for this occurrence could be the fact that those who have stayed in relationship shorter than 6 months may not be confident enough to discuss HIV issues with their partners for fear of being blamed for bringing the virus into the relationship let alone losing the relationship at its infancy. Such similar situations are very fertile grounds for breeding domestic and gender based violence in many homes in Uganda. Contrary, a study conducted in California to determine the Uptake of HIV services among men and women infected with HIV showed no significant relationship reported between marital status and uptake of HIV services by adults (Koop man et al, 2004).

Knowledge of the signs and symptoms of HIV in children was closely related to utilisation of HIV services for children by the HIV positive mothers. We can also assume that since these mothers are living with the virus themselves it becomes easier for them to distinguish between the most common symptoms of HIV and thus relate them to that of children. This knowledge is also partly as a result of the continuous education given by many health facilities providing HIV care and treatment to their clients as part of a comprehensive HIV treatment program. Secondly we can also assume that if a mother did receive prevention of Mother to child transmission HIV

services (PMTCT) during pregnancy there is a possibility that she may have been sensitised about the most common symptoms of HIV in children. This finding actually is in agreement with the findings conducted in South African among Tuberculosis patients which showed that knowledge on relationship between symptoms of TB and HIV was the strongest predictor of HIV testing service utilisation among TB patients (Kigozi et al, 2010).

5.2 Environmental factors

Mothers who feared being discriminated against by their family members were less likely to utilise HIV services for their children compared to those who didn't fear. Fear for the unknown is a major challenge even in day to day life. Many people live in constant fear and in the process fail to face up to their challenges. Most HIV positive mothers who are currently accessing HIV care and treatment were able to overcome their own fears to access these services but similar fears are still haunting them and preventing them from accessing similar services for their children. On the other hand, some mothers may not have disclosed their status to their partners and would prefer it remains a secret least they risk losing their marriages or even face domestic violence. However, irrespective of the repercussions on the side of the mother, we know that this is a direct abuse of children's rights to proper Health care.

To elaborate further, a study conducted in Cape Town South Africa to establish the major barriers to uptake of HIV services by people infected with HIV agrees with the findings of this study .The South African study reported that people living with HIV/AIDS found it difficult to uptake HIV services for fear of being rejected and discriminated against (Allanise et al 2010). The same study also pointed out the fact that fear causes a lot of anxiety by the mothers about the

future of their children which affected their decision to disclose to any family member let alone the children themselves.

Another important finding was that directly related to power relations in the home. Mothers who said they were the main decision makers in the home were 2.5 times more likely to utilise HIV services for their children compared to those who said their partner was the main decision maker. This finding is not surprising because the concept of gender and power relations has been established by many studies as a hindrance to use of health services especially by women. Women who have no say in major family decisions including financials are very vulnerable to gender based violence and abuse and this directly impacts on their children as well. On the other hand families where women have access to family resources and are central in the decisions making processes for their families tend to have better access to services including health services for both themselves and their children. It is encouraging to compare this finding with those of a study that used bibliographic data searches to analyse the gender relations (Hirsch, 2007). The study revealed that utilisation of HIV/AIDS services is closely related to the intersection of gender and antiretroviral therapy utilisation. The study further established that the gendered division of labor and the gendered power inequalities in relationships shape utilisation of HIV/AIDS services.

5.3 Facility Factors

Although none of the facility factor showed a significant relationship with utilisation of Paediatric HIV services by the HIV positive mothers, they still remain important factors to control for as seen from the responses from the focused discussion. Mothers expressed a lot of concern about the waiting time, dissatisfaction on the small number of doctors at the facility

which contributed to the delays in receiving services on the side of patients, low quality of education given to clients as pertain the importance of HIV treatment. These factors still came out strongly in a similar study conducted in South Africa. A significant relationship was reported between limited skilled human resources and uptake of paediatric HIV services (Tammy et al, 2006).The low number of skilled health workers in managing children infected with HIV is closely linked to the fact that mothers feel abit underserved when it comes to HIV services for their children. It is common knowledge that mother tend to look out for the best doctors who have the techniques and skills in handling children. This gives them confidence that even the quality of treatment received is good. Besides the availability of skilled health workers, the number also matters a lot. In this particular study despite showing any significance, mothers reported that the number of doctors at the facility is actually small and that the small number of doctors directly impacts on their length of stay at the facility which also discourages many from seeking health services as reported by the South African study.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

Introduction

This chapter presents the recommendations and conclusions resulting from the study of the factors influencing utilisation of Paediatric HIV services by HIV positive mothers that can facilitate designing of appropriate and effective interventions to support HIV positive mothers utilise paediatric HIV services for their children.

Conclusion

This study was a cross sectional survey aimed at establishing the factors influencing utilisation of Paediatric HIV services by 320 HIV positive mothers received HIV care and treatment at Kamwokya Christian Caring Community in Kampala district. The study revealed that only 49% of the mothers had ever utilised paediatric HIV services. A multivariate analysis of the factors considered to influence utilisation of paediatric HIV services revealed that awareness of availability of free HIV services for children was an independent predictor of utilisation of paediatric HIV services by the HIV positive mothers. None of the environmental and facility factors showed a close association with utilisation of Paediatric HIV services at multivariate level.

Recommendations

Based on the findings of this study, the following recommendations need to be considered by KCCC, HIV program implementers and policy makers to inform the designing of appropriate and effective interventions to support HIV positive mothers utilise available HIV services for their children.

Psychological preparation of patients prior to starting Anti-retroviral therapy is of high importance to enhance utilisation of HIV services for both the mothers and their children. This should involve clear messages on how HIV drugs work to prolong life as well as the pros and cons of being on medication. This will help mothers make informed decisions that they will even facilitate good adherence. In addition HIV program implementers should note that pre- ART education and adherence education are a very critical package of any HIV treatment program in the sense that it builds up a patient's level of knowledge about HIV care and treatment and enhances their utilisation and adherence levels.

To address the issue of waiting time Kamwokya Christian caring community could consider having special appointment days for only children and their mothers and if possible on weekends. This will help ease on the congestion at the clinic as well as provide an opportunity for the mother, child and health worker to interact more freely.

Programs should scale up community outreaches and home visits to better provide opportunities where health workers and parents are able to discuss at length any issues surrounding their fears to uptake services for their children. Currently due to limited funding many HIV health services providers have cut back on this activity yet its important.

HIV implementing agencies should advocate for increased funding for home based HIV counseling and testing services as this bring services nearer to the people especially those who have stigma related challenges to utilisation of similar services at the Health facilities.

REFERENCES

AIDS Today (2010-2011). "Universal Access and Human Rights: I have a duty to protect every child from HIV/AIDS Do you?" An Annual publication in partnership with Uganda AIDS Commission, Issue 9 page 7

AIDS Care (2010)." Factors Influencing Utilisation of HIV care and treatment among Children in South Africa". A qualitative study of caregivers and Clinicians. Volume 22, Issue 9. Page 1101

Allanise Colette, Ana Strebel, Leickness Simbayi, Brian Van WYK, Nomvo Henda, Ayanda Nqeketo (2010). "Challenges faced by people living with HIV/AIDS in Cape Town, South Africa: Issues for group risk reduction interventions". AIDS Research and treatment. Vol.2010, Article ID.420270

Amelia R. Turagabeci, Keiko Nakamura, Masash Kizuki, Takeniti Takano (2007). "Family Structure and Health, How companion acts as buffer against ill health". www. Hqlo.com/content/5/1/61. International journal of Health Geography. Viewed on 22nd/9/2011 at 1.22pm

American Academy of Paediatrics (2007). "Increasing Anti-retroviral drug access for children with HIV infections". Vol.119. www.paediatric.appublications.org

Averting HIV and AIDS (2011). "Children, HIV and AIDS" www.avert.org/children.htm

Basic Support for Institutionalizing Child Survival (2006). "Report of a paediatric HIV/AIDS Care and Treatment Assessment in the Kilimanjaro, Iringa and Mbeya regions of Tanzania". Arlington, Virginia USA.

Braun. M, Kabue.M.M, Mc Collum.E.D, Ahmed.s, Kim. M, Aertker. L, Chirwa. M, Eliya.M, Mofolo.L, Kline.M.W, Hosseinipour.M.C (2011). "Inadequate Coordination of Maternal and Infant HIV services Detrimentally Affects early diagnosis outcomes in Lilongwe Malawi" Jacquir Immune defic Syndrome. http://www.ncbi.nlm.nih.gov/pubmed/21224736/

Claude Ann Mellins, Elizabeth Brackis-Cott, Curtis Dolezal, Ana Richards, Stephen W. Nicholas, Elaine J. Abrams (2002). "Patterns of HIV status disclosure to parentally HIV infected children and subsequent mental Health outcomes". Clinical Child Psychology and Psychiatry. Vol.7 Sage Journals.

Human Rights Watch (2007). "Hidden in the Mea lie Meal Gender-Based Abuses and Women's HIV Treatment in Zambia".Vol.19 No18. Pg. 1

International Community of Women Living with HIV/AIDS (2008). "HIV positive women, Pregnancy and Motherhood" a briefing paper Pg 4. www.icw.org

Joint United Nations Programme on HIV/AIDS (2010). UNAIDS 2011-2015 strategy. Getting to Zero. WHO Library Cataloguing. www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/jc2034_

unaids_strategy_en.pdf

K.N. Muko, GKT Changwe, V.C Ngwa, L. Njoya (2004). "Preventing Mother to Child Transmission: Factors affecting mother's choice of feeding". A case study from Cameroon. Journal of Social Aspsects of HIV.

Goujard, C., Bernard, N., Sohier, N., Peryamond, D., Lancon, F., Chwalow, J., Arnould, B., Delfraissy, J., (2003). Impact of a Patient Education Program on Adherence to HIV Medication: A Randomized Clinical Trial. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. October 2003 - Volume 34 - Issue 2 - pp 191-194.

Hirch, J., (2001). *Gender, sexuality and antiretroviral therapy: using social science to enhance outcomes and inform secondary prevention strategies*. Department of Social medical sciences school of public health, Columbia University USA.

Kalichman, S., Bineetha, R., Catz, S., (1999). Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *Journal of General Internal Medicine Volume 14*, Issue 5, PP. 267–273.

Karusa Kiragu, Avian Sarna, Katie Schenk (2007), "Kenya Paediatric HIV/AIDS Study". Horizons National dissemination workshop.www.popcouncil.org/pdfs/horizons/

Heunis JC, Chikobrup, Van den Bergh, Van Rensburg HC, Wovterse (2010). "Predictors of utilisation of human immunodeficiency virus testing by Tuberculosis patients in Free State province, South Africa. University of Free State.

Lindsay Jeanne Leininger, Kathleen M Ziol- Guest (2006)." Examining the effects of Family structure on Children's Access to Care: The single father Family". www.cfah.org.Journal of Health Services research Vol 43.

Lori Bollinger, John Stover, Eleni Seyoum (1999). "Economic Impact of AIDS in Ethiopia". Research Triangle Institute.

Markus hacker (2004) . "The Macro economics of HIV/AIDS. International Monetary Fund" http://www.imf.org/external/pubs/ft/aids/eng/index.htm.Pg 169

Mariam M. Mohamed, Abubaki M. Nasi, Dar Elgalal A. Abdalehafiz, Mohamed.A.Elsheikh, Ishag Adam (2007). "Knowledge and attitude towards HIV Voluntary Counseling and testing services among pregnant women attending an antenatal clinic in Sudan". Journal of Medical Virology, Volume 79, Issue 5 page 469.

Melinda Stanner, Han Tin French, (2005). "Empirical study of the relationship between situation awareness and decision making "*DSTO Systems Sciences Laboratory, Edinburgh South Australia*

www.dtic.mill

Ministry of Health (2010). "Annual Health Sector Performance Report". Financial Year 2009/2010, page 21

Ministry of Health (2010). "Paediatric HIV Communication campaign Strategy". Page 1,3,4

R. Kandwal (2007). "Link to Slow Access to Care: What is the Stigma? An Indian perspective" Springer Science Business Media, LLC. http//www.resources.metapression. PubMed. Viewed at 3.20pm on the 23rd/9/2011

Remien, R., Chowdhury, J., Mokhbat, J., Soliman, C., Adawy, M., Wafala, E., 2010. "Gender and care: Access to HIV testing care and treatment". HIV Center for Clinical and Behavioral Studies, *Acquired Immune Deficiency Syndrome*. 2009 pp. 106-10.

Tammy Meyers, Harry Moultrie, Kimesh Naidoo, Mark Cotton, Brian Eley; Gayle Sherman (2006). "Challenges to Paediatric HIV Care and Treatment in South Africa" Oxford journal of Infectious disease. Volume 196, Issue supplements 3.

T.J Rochat, A.Stein, L.Richter (2008). "Women's feelings, altitudes and experiences on learning their HIV status during Pregnancy in Rural South Africa". Xvii Interntional AIDS Conference. www.iasociety.org

Uganda Bureau of Statistics (2009/ 2010). "Report on the Uganda National Household Survey". www.ubos.org

United States Agency for International Development (2009). "Health Policy Initiative- Health seeking Behavior in Rural Uttar Pradesh: Implication for HIV prevention, Care and Treatment". http//www.healthpolicy initiative.com/publications/documents. Viewed on the 23rd/9/2011.

United States Agency for International Development (2011). "Foundation for the Future: Meeting the Psychosocial needs of children living with HIV in Africa". AIDSSTAR- One

United States Agency for International Development (2011). "HIV/AIDS Health profile report": http//www.usaid.gov/ourwork/global-health/aids/countries/asia. Viewed on the 30th/9/2011.

United Nation Programme on HIV/AIDS (2011). "Report on the global health, AIDS epidemic". Geneva: http://www.kff.org/hivaids/upload/3030-13.pdf

World Health Organization (2005). "What is the impact of HIV on families? A report of Health Evidence network". http://www.euro.who.int/Document/E87762.pdf

Yeap AD, Hamilton R, Charalambous S, Dwadwa T, Churchyard GJ, Geissler PW, grant AD (2010). “Factors influencing uptake of HIV care and treatment among children in SouthAfrica. Pub med 1101-7

APPENDIX 1: INFORMED CONSENT FORM

Title of the study

Factors influencing the Utilisation of Paediatric HIV services by HIV positive mothers.

Introduction

My name is Irene Naikaali; I am a student pursuing a Master of Business Administration/ Health management degree at International Health Sciences University. Iam conducting the above study as a requirement for the partial fulfillment of my masters' degree. This form is meant to explain to you some of the important details about the study before you give your consent to participate. Once you agree to participate in the study, you will be requested to sign this form in duplicate and a copy will be given to you.

Purpose of the study

The purpose of the study is to establish the Factors influencing the utilisation of paediatric HIV by HIV positive mothers. It has been realized that despite the availability of free HIV services in many of the health facilities in Uganda of the 42,000 children in need of treatment only 41% are able to access HIV services. Surprisingly though data available also shows that HIV positive parents are accessing these services in large numbers but not their children. Therefore study seeks to focus on the HIV positive mothers already accessing services from KCCC to understand the factors that may be hindering them from accessing similar services for their children.

Study procedures

If you agree to participate in the study, you will be asked some question about utilisation of HIV services for children in general and also your demographic, social cultural, economic and facility factors that may be associated with the utilisation of paediatric HIV services.

Risks

There are no risks involved in this study.

Benefits

There are no direct benefits to you for participating in this study. However, the information generated from this study will assist policy makers, health care providers as well as other stakeholders to effectively plan for interventions to support parents improve utilisation of Have services for their children.

Costs

There will be no costs incurred to you for participating in this study and you will not be paid for taking part in this study.

Questions about this study

If you have any questions about the study, please contact the researcher Mrs. Irene Naikaali on telephone number 0772627241

Participants' consent

I have agreed that by signing this consent, I have been provided with all the information about the study. Participation in the study is voluntary.

Participants' name …… signature…… date…….

APPENDIX II: Questionnaire for the HIV positive Mother

Date of interview ----------

Participant's Identification number ----------

Interviewer ----------

Question Number	Question	Answer Choices(Circle the response that corresponds to the answer)
Maternal Factors		
1	Age of respondent (In complete years)	
2	Highest level of Education attained?	a) None b) Primary c) O Level d) A Level e) University/Tertiary
3	Religion of Mother	1) Catholic 2) Protestant 3) Muslim 4) Adventist 5) Pentecostal 6) Others(specify)
4	Location of residence	1) Urban 2) Rural
5	Marital status	a) Single b) Married c) Cohabiting d) Separated e) Widowed
6	If you are married/ cohabiting, for how long have	1)<6 months

	you been in this relationship?	2). > 12 months
7	What are you currently doing to earn a living?	a) Formally employed b) Self employed c) Unemployed d) Other(specify)
8	Please rate the level of your monthly income	1)Less than 150,000/= 2)Above 150,000/=
Utilisation of paediatric HIV services		
9	How many children (0-14years) are you currently taking care of?	
10	Do you agree that children who have not yet been tested can have the HIV virus but still look very healthy?	1 Agree 2 Disagree 3 neutral
11	Do you know of any HIV symptom in Children?	1 Yes 0 No
12	If yes to question 12, mention any 2 symptoms of HIV in children.	
13	Are you aware that there are free HIV services for children in many hospitals and health centers in Uganda?	1 Yes 0 No
14	Have any of your children ever been tested for HIV?	1) Yes 0 No
15	How many of your children have at least been tested for HIV?	1 <2 2>3
16	How many are currently accessing HIV care and	A) All of them

	treatment services	B) Only one C) None of them D) Other(specify number)
17	Which services are they currently accessing*?* *(please tick what applies)*	a) ART b) Septrin and other OI treatment c) Paediatric counseling services d) Other HIV care support services (Life skills, Education, and Food etc.)
18	Where are they currently accessing these services from? *(please tick what applies)*	1 KCCC 2 Baylor college of medicine 3 Mild May 4 Nsambya Home care 5 MJAP 6 Mulago hospital 7 Other(specify)
19	Please rate your overall level of utilisation of HIV services for your child/children	a) Less than 20%(poor) b) Between 21- 50%(fair) c) Between 51- 80 %(Good) d) Above 81% (Very good)
Environmental factors.		
20	Who is the head of your household	a) Myself b) Partner(husband, boyfriend) c) Relative d) Other(specify)
21	Occupation of the household head	1) Formally employed 2) Self employed 3) Unemployed

22	Who is the main decision maker in the household	1) Partner 2) Self 3) Relative 4) Other
23	Have you ever disclosed to any member of your family about your HIV positive status*?(if no skip to qtn 30)*	0 Yes 0 No
24	If yes to above question, has this disclosure facilitated your utilisation of HIV services for your children?	1 Yes 0 No
25	*If no to question 28*, what are some of the reasons why you have not disclosed.	1 Fear 2 Culturally inappropriate 3 Stigma 4 Lack of knowledge on services 5 Other(specify)
26	Would your household members accept an HIV positive child in your family?	1 Yes 2 No 3 Don't know
27	Would you disclose to a family member that any of your biological children is HIV positive?	1 Yes 0 No
28	Do you agree that not disclosing to any family member that a child is HIV positive hinders their utilisation of HIV services?	1 Yes 0 No
29	Do you agree that not disclosing to a child about their HIV positive status (at an appropriate age) hinders their utilisation of HIV services?	1 Agree 2 Disagree 3 Neutral

30	Do you belong to any parent/ care giver psychosocial support group in your community?	1) Yes 2) No
31	If yes to above question, has your support group helped you to access HIV services for your child/children?	a) Yes b) No
Facility factors		
32	On a scale of 1-5 please rate the quality of services at KCCC in general.	1) Very good 2) Good 3) neutral 4) Poor 5) Very poor
33	Are HIV services for children readily available every time they are needed at this facility?	1 Yes 2 No 3 Don't know
35	Are the HIV drugs given for children easy to use?	1 Yes 0 No
	If no please explain why?	
36	Are the HIV drugs given for children easy to store?	1 Yes 0 No
	If no please explain why?	
37	Do you agree that the time taken waiting to receive a service for your child affects your future decision to access services?	1) Agree 2) Disagree 3) Neutral

38	How far is your home to the nearest health facility providing HIV services for children?	1) Less than 1 mile 2) Between 1mile to 3 miles 3) More than 3 miles
39	Do you consider KCCC far from your home?	1 Yes 0 No
40	Are there additional costs incurred by clients for HIV services for Children at this facility?	1 Yes 2 No 3 Don't know

APPENDIX III: Focused Group discussion guide
Factors influencing the utilisation of Paediatric HIV services by HIV positive mothers.

Date……..

Interviewer…….

1- What HIV services are available for children at this facility?

2- How would you describe the utilisation of these services by HIV positive mothers already receiving HIV care at this facility?

3- What are some of the reasons you would give to explain why the number of children receiving care at this facility is low?

4- Why do you think HIV positive mothers at this facility are not bringing their children to benefit from the HIV services being provided?

5- What can be done to support the HIV positive mothers at this facility utilisation HIV services for their children?

APPENDIX IV: Budget

Item	**Unit Cost**	**Quantity**	**Frequency**	**Total cost**
<u>Stationary</u>				
-Realm of Paper	18000	5	1	90,000
-Pens	500	3	1	1500
-Pencils	400	6	1	2400
-Notebooks	1500	1	1	1500
Transport	10000	4	12.5 days	40000

Research Assistant fees	50000	3	12.5 days	1,875,000
Communication/Airtime	20000	3	1	60,000
Printing of questionnaires	2000	391	1	782,000
Printing draft dissertation for review	15000	1	4	60,000
Printing and Binding of Final dissertation	30,000	2	1	60,000
Grand Total				**2,877,000**

Budget Narrative

The total estimated budget for the study is UGX 2,877.000. As already indicated in the table above, the budget will cover the following line items;

Stationary: This will include, realm of paper to facilitate photocopying of the questionnaires, pencils to be used by the research assistants during data recording, a note book for note taking during the key informant interviews.

Transport: The total amount budgeted for transport is to facilitate movement of the research team from the city center to the study center during the data collection days.

Research Assistant fees: Each of the 3 research assistants will be paid professional fees of UGX 50,000 for the 12.5 days of data collection. They will be expected to cover their own meals using this money.

Communication: Each of the research assistants will be given amount UGX 10,000 for airtime to only be used for purposes relevant to the study. Such as communicating to the researcher on any emerging issues during data collection.

Printing of Questionnaires: A total of 391 questionnaires will be printed to be administered to the respondents. These include an extra 20 tools to cater for any damages.

Printing of draft dissertation: Prior to submission of the final dissertation, a draft copy of the final will be printed and handed in to the research supervisor for review. This copy will be a lot similar to the final dissertation copy.

Printing and Binding of the Final dissertation: Two copies of the final dissertation will be printed and bind ready for submission to the University. One of the copies will be retained by the researcher while the other will be handed in.

APPENDIX V: Work plan

Activity	March	April	May	June	July	August	September
Proposal writing							
Soliciting for Research assistants							
Training of RA							
Pretesting of Questionnaires							
Data Collection							
Data Entry							
Data Analysis							

Results interpretation and presentation							
Report writing							
Presentation of results							
Dissemination of results							