



**KAMUZU COLLEGE OF NURSING**

**REPRODUCTIVE HEALTH NEEDS AND SEXUAL PRACTICES OF FEMALE  
ADOLESCENTS WITH PERINATALLY ACQUIRED HIV**

**MASTER OF SCIENCE (CHILD HEALTH NURSING) THESIS**

**By**

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**BSc (Nursing Education), PGD (Child Health Nursing)**

Submitted to the Faculty of Nursing, in partial fulfillment of the requirement for the award of the  
degree of Master of Science in Child Health Nursing.

**JANUARY, 2017**

## **DECLARATION**

I, Beatrice Mkandawire, hereby declare that this thesis titled "**Reproductive Health Needs and Sexual Practices of Female Adolescents with Perinatally Acquired HIV**" is my original work and that I have not submitted it or any part of it for a degree at any other University within or outside Malawi. Work of other people used in this thesis have been indicated and acknowledged as complete references.

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## **CERTIFICATE OF APPROVAL**

We the undersigned hereby certify that this thesis is the student's original work and effort and has been submitted with our approval.

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### **Co-Supervisor**

## **DEDICATION**

This thesis is dedicated to my late father Frankson Banda, who always inspired me to achieve great things in life. Dad, you will always live in my heart. To my beloved husband, Sangwani Kaswaya, thank you for the enormous support and for believing in me. My children, Sangwani (junior), Loyerwe, Velepi and Nkululeko, you have been a source of inspiration through your support and encouragement. You have been a blessing and thank you for believing and trusting me. May God Almighty grant his blessings to you all!

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## **ABBREVIATIONS AND ACRONYMS**

<b>AIDS:</b>	Acquired Immunodeficiency Syndrome
<b>ALHIV:</b>	Adolescents Living with HIV
<b>ART:</b>	Anti-retroviral therapy
<b>ARV:</b>	Anti-retroviral
<b>BIPAI:</b>	Baylor College of Medicine International Pediatric AIDS Initiative
<b>FP:</b>	Family Planning
<b>HIV:</b>	Human Immunodeficiency Virus
<b>MDG:</b>	Millennium Development Goal
<b>MOH:</b>	Ministry of Health
<b>NSO:</b>	National Statistical Office
<b>NAC:</b>	National AIDS Commission
<b>PLWH/A:</b>	People living with HIV and AIDS
<b>SRH:</b>	Sexual and Reproductive Health
<b>SSA:</b>	Sub-Saharan Africa
<b>UNFPA:</b>	United Nations Population Fund
<b>UNICEF:</b>	United Nations Children's Fund

**UNAIDS:** The Joint United Nations Programme on HIV/AIDS

**WHO:** World Health Organization

**YPLHIV:** Young People Living with HIV

**YFS:** Youth Friendly Services

## **OPERATIONAL DEFINITIONS**

**Adolescents:** are young people, female or male, aged 10-19 years

**Adolescence:** is defined as a stage of life during which individuals reach sexual maturity; it is the period of transition from puberty to maturity.

**Antiretroviral Therapy:** Antiretroviral therapy for HIV infection consists of drugs which work against HIV infection by slowing down the replication of HIV in the body. The treatment consists of drugs that have to be taken every day for the rest of a person's life.

**Reproductive Health:** Reproductive health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity in all matters relating to the reproductive system and to its function and processes (WHO, 2006).

**Sexually active:** an individual is considered sexually active or experienced if she or he has ever had heterosexual intercourse at least once in their life time.

**Youths:** are all young people female or male from age 14-25 years

**Youth friendly services:** these are health services of high quality that are attractive, affordable, appropriate and accessible to youths.

**Note:** Although adolescents are defined as young people aged 10-19 years, in order to avoid monotony, different terms such as adolescents, youths and young people are used in the study, all meant to refer to people aged 18-19 years.

## **ABSTRACT**

**Introduction:** The advent of Anti-retrovirals (ARV), a life longing drug, has enabled more and more children with perinatally acquired Human Immunodeficiency Virus (HIV) to reach adolescence, a situation which was not anticipated. These adolescents are at a stage where they are making transition from childhood and are undergoing physical and emotional changes and begin sexual exploration hence are vulnerable to HIV re-infection and other sexual infections. However, to date, this group has received relatively less attention in the field of reproductive health care as most of such services are adult centered. The aim of the study was to explore reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV.

**Methods:** An exploratory study utilizing qualitative approach was conducted at Baylor College of Medicine-Lilongwe District, Malawi. A total of ten female adolescents with perinatally acquired HIV, aged between 18-19 years were purposively selected and interviewed using a semi structured interview guide. All the interviews were audio taped and transcribed verbatim. Thematic Analysis (TA) was used to analyze data manually.

**Findings:** The study findings have shown that access to comprehensive health information and services remains a challenge. Participants expressed ignorance on other reproductive options available and how to use them. The study revealed that the desire to have children in future was common amongst participants. Participants showed understanding of

contraception. However, there seemed to be a huge gap between their knowledge of different types of contraception and access to these services. The study demonstrated that the commonly used contraception was injectable form, due to the secrecy surrounding it. It was noted that participants were sexually active. However, they were not using dual protection methods of contraception despite their HIV sero status.

**Conclusion:** ALHIV need more information, skills, and support to practice healthy behaviours. Tailored interventions are required for adolescents living with HIV to improve their sexual and reproductive health.

**Key search terms and parameters**, sexual reproductive health, needs, sexual behaviour, adolescents, perinatally acquired HIV.

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## **CHAPTER 1**

### **INTRODUCTION AND BACKGROUND TO THE STUDY**

#### **Introduction**

The advent of Anti-retrovirals (ARV), a life longing drug, has enabled more and more children with perinatally acquired Human Immunodeficiency Virus (HIV) to reach adolescence, a situation which was not anticipated (Gortmaker et al., 2001). Initially HIV was perceived by many as a life-threatening disease; however, there has been a significant shift in recognition that HIV can also be managed (World Health Organization [WHO], 2006). The use of ARVs which delays HIV progression and the increased acceptability of adolescents with perinatally acquired HIV have led to renewed hope and courage in lives of many (Gortmaker et al., 2001). Whether these have also improved the desire for reproductive health and to engage in romantic relationship and have children for adolescents with perinatally acquired HIV needs a closer look.

This period of adolescence is characterized by a number of changes, including physical and emotional changes, the search for identity and greater maturity in reasoning. Adolescents are at a stage where they are making transition from childhood and are undergoing physical and emotional changes and begin sexual exploration (Shire, Ahmed, & de Bruyn, 2005) as adolescents go through these changes, they tend to experiment with such activities as sexual intercourse. Many adolescents adopt risky behaviours without

having adequate or correct information on how to protect themselves from the adverse consequences of such behaviour (WHO, 2006).

As is elsewhere in sub-Saharan Africa (SSA), social and cultural norms restrict the discussion of reproductive health (RH) issues and sexual practices between adolescents and adults (Neema, Musisi. & Kibombo, 2004). In addition, reproductive health needs and sexual practice have rarely been the focus of programmes in perinatally acquired HIV adolescents; instead unmet need for contraception and sexual practices have been addressed by programmes in adults and the general population of adolescents (Neema, Musisi & Kibombo, 2004). Furthermore, provision of Sexual and Reproductive Health (SRH) care services to adolescents continue to be negatively affected in Malawi by lack of advocacy for laws to lower the age of consent for testing and treatment, and yet this is a country where an estimated 14.3% of the youths aged 15-24 had sexual intercourse before age 15 (MDHS, 2010), currently the minimum age for consent is 18 (MDHS, 2004).

It is believed that, illness alters one's participation in social life and relationships as well as one's sense of self. Meanwhile, Cooper et al. (2005); Harries et al. (2007) and London et al. (2008) described the effects that HIV has on respondents' daily lives, by analyzing ways in which living with HIV has shaped their identities. The studies compared the experiences of HIV positive female adolescents with other populations and came up with the obstacles which they face, among others, female adolescents, unlike their male counterparts, face challenges such as reproductive decisions, access to health care and social services due to stigma.

A study in Cape Town examined the reproductive needs and choices of adolescent living with HIV and concluded that they needed to be empowered to make informed choices about their own reproductive health needs (Speizer & White, 2008). Moreover, according to UN (2015), Malawi is committed to ensuring Sustainable Development Goal 3 (Ensure health lives and promote wellbeing for all ages). Ensuring health lives and promoting the wellbeing for all at all ages is essential sustainable development (UN, 2015). It is remarkable to note that significant strides have been made in increasing life expectancy and increasing access to reducing spread of HIV/AIDs, and reducing some of the common killers associated with child and maternal mortality (UN, 2015). However, calls for specific focus on ensuring that relevant and targeted SRH policies and services that respond to the particular needs of adolescents, particularly those living with HIV need to be in place. Therefore, this study contributes to literature on reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV

## **Background to the Study**

### **HIV and AIDS epidemiology: global and sub-Saharan overview**

Globally an estimated 33.3 million people living with HIV was registered by 2010, of which 2.2 million were children under the age of 15 years (United Nations Programme on HIV/AIDS [UNAIDS], 2010), at the end of 2013 there were an estimated 35 million people living with HIV (UN, 2015). Despite the increase in new HIV infection in 2013, which were estimated at 2.1 million, the prevalence is 38% lower than 2001 (UN, 2015). With regard YPLHIV, 2.1 million adolescents were living with HIV as of 2013, of these 250 000 were new HIV infections among adolescents and two thirds were among

adolescent girls (UN, 2015). However, new HIV infections in children (acquired perinatally) have declined by 43% from 2003 to 2011 (UNAIDS, 2012). Even though, new HIV infections in children declined by 43% from 2003 to 2011, more than 2,400 young people are reported to be infected with HIV each day (UNAIDS, 2012), a development which implies the gravity of risky sexual behaviours among young people in the region.

More than 90% of paediatrics HIV infections are due to mother-to-child transmission (MTCT), It is likely that the number of perinatally HIV infected young people will continue to escalate and that they will survive into young adulthood in the coming years (UNAID, 2012), This is attributed to increased access to life-prolonging drugs (Family Health International, 2009). Overall 90% of these infections occur in sub-Saharan Africa (UNAIDS, 2010). In Malawi since the first case of HIV was discovered in 1985, there has been a relatively high prevalence rate of the infection that is currently at approximately 10.6 % (Government of Malawi, 2010).

Similarly, Malawians have witnessed an increase in HIV prevalence among pregnant women since the diagnosis of the first case of AIDS in 1985 (National AIDS Commission, 2009). In 1999 the prevalence reached a peak of 22.8% and started declining in 2001, similar decline was noticed in mother to child HIV transmission from 21.3% in 2004 to 12.8% in 2010. Children living with HIV were estimated at 100,000 in 2009, and over 90% acquired HIV perinatally (National AIDS Commission, 2009). Likewise, it has been acknowledged that HIV prevalence among young people has declined over the period 2004 to 2010, overall, the HIV prevalence among young people (15-24) decreased from 6% in 2004 to 3.6% in 2010 (Government of Malawi, 2012). For adolescents aged 15-19, the overall HIV prevalence in 2004 was 2.1% (with women accounting for 3.7% and men for

0.4%), which increased to 2.7% in 2010 (4.2% for females and 1.3% for males) (Government of Malawi, 2012). These figures comprise both those who acquire HIV during adolescence and through vertical transmission and have lived to adolescence or young adulthood (Mwalabu, 2014). The precise HIV prevalence data on perinatally HIV infected young people is currently not available for Malawi.

Global youth coalition on HIV/AIDS (2007) highlights the fact that the exact numbers of adolescents with perinatally acquired HIV are hard to determine because HIV data is normally disaggregated between adults and children. Even though the prevalence of adolescents with perinatally acquired HIV is difficult to determine, information from Baylor College of Medicine Children's Foundation-Malawi clinic in Lilongwe indicate that a better approximation would be using all the children that enrolled at the site as exposed and have become infected and the percentage of such is 11.9% of the total HIV infected.

It is however evident that their population is steadily growing across the globe. For instant in United States of America (USA) since the introduction of ARV therapy in the mid-1990s, life expectancy of children who were infected perinatally with HIV has increased substantially (Chibber & Khuranna, 2005). Similar trends were noticed in selected areas such as the North-Eastern province of India (Manipur) where foreign aid has been satisfactorily channelled to issues pertaining to HIV, this resulted in the number of perinatally HIV infected children increasing (Chibber & Khuranna, 2005).

A study done in Brazil, Argentina and Mexico among 109 adolescents aged 12-19 revealed that majority of the participants 61% had lived with HIV since infancy. The study underlines the fact that significant numbers of young positives will reach adolescence with

access to antiretroviral drugs (Mialky et al., 2001). Studies have confirmed that youths are the most vulnerable to HIV/AIDs in sub-Saharan Africa (Fatusi & Hindi, 2010; Akinyemi & Okpechi, 2011). The adolescents and young adults are disproportionately affected.

One study in Malawi found that 20% of young people aged 15–23 were HIV-positive (The Alan Guttmacher Institute, 2005). However, young women are particularly vulnerable; they are five times more likely to be infected than their male counterparts. For instance, data in Malawi show that the HIV prevalence rate among girls and boys aged 15–19 years is 4% and 1% respectively (NSO, 2011). Adolescents are the future generation whose health needs are to be addressed in order to secure a healthful and productive nation, hence reports indicate that by 2004 antiretroviral therapy (ART) access was scaled up in Malawi so much that about 200,000 patients had initiated treatment, of which 10% were children (Stover et al., 2010). Furthermore, by the end of 2010 data indicate that, the Queen Elizabeth Central Hospital ARV clinic had 1,956 children registered for HIV care service. At this time 1,001 of these children were alive and on ART and 437 of them were adolescents aged 10-19 years. Data from Baylor College of Medicine Children's Foundation-Malawi Clinic in Lilongwe indicate that by 2013 a total of 2,064 children were registered for HIV care service; of these 527 were adolescents aged between 13-20 years. Therefore, with antiretroviral drugs, children who get infected at birth with HIV have an opportunity to graduate into adolescence.

Baryamutuma and Baingana (2011) rightly observes that as the population of perinatally infected adolescents grows, service providers and stakeholders need information to effectively respond to their evolving needs, most importantly responding to their SRH needs. However, WHO (2006) notices that the difficulties of working with adolescents on

issues of SRH are made even more complex for those living with HIV; key interventions to alter disease transmission and prevention of pregnancy among them have tended to emphasize delaying sexual debut, reducing the number of sexual partners, and increasing correct and consistent condom use. A major limitation though is that, these interventions have mainly focused on the adolescent in general, which is assumed to be either HIV negative or unaware of their HIV status (Birungi et al., 2008), this leaves a gap in information and reproductive service provision to adolescents with perinatally acquired HIV.

According to Mugoni (2011), Southern Africa is characterized by shortages of dedicated youth-friendly clinics where young people are encouraged to meet and discuss issues pertaining to their reproductive health, such as access and use of contraceptives, including condoms. However, Mugoni (2011) indicates that with the exceptions of Malawi and South Africa, the two countries have done well in scaling up the number of dedicated clinics for the adolescents in implementing strategies to enhance uptake of these services.

The Ministry of Health (2011) in Malawi, acknowledges the fact that national expansion of HTC and ART has produced successful results, such that there has been an increase in the number of individuals accessing ART from around 4,000 in 2004 to 365,191 by the end of March 2011. In the same way country-wide ART sites increased from just nine in 2003 to 491 in 2009, 50% of which are community-based indicating easy accessibility to health services (Fasawe, 2013). Likewise, the policy of universal and free access to ART has reduced annual HIV related deaths from 88,000 in 2005 to 53,000 in 2010 (Ministry of Health, 2011), and has resulted in many children surviving to adolescence and young adulthood. For instance, by December 2009, Baylor Centre of

Excellence had commenced 2,103 children (including young people) on HIV treatment, representing approximately 10 percent of all children ever initiated on ART in Malawi (Baylor College of Medicine, 2009). The remarkable success in the treatment of paediatric HIV has changed the face of the epidemic from a progressive fatal disease to a chronic health condition among young people as they grow up to young adulthood (Mwalabu, 2014).

In addition, Malawi is currently implementing strategies to improve reproductive health delivery services (Ministry of Health, 2009). For instance, the SRH policy recognizes key priorities for a comprehensive program, comprising family planning, young people in reproductive health, male involvement in reproductive health and resource supporting system. The country has expanded youth-friendly SRH services to 1,609 health facilities, an increase from eight per cent in 2004 to 85 per cent in 2010 (Mugoni, 2011). Furthermore, Malawi developed a Guideline for Management of HIV in Children and Adults (Ministry of Health, 2011). In this guideline there is information on HIV Care Clinic (HCC), which is a further Integration of clinical HIV service designed to facilitate access for clinical monitoring, preventive services and ART for family members affected by HIV. The following services are supposed to be offered together at the same time. Follow up of HIV exposed children, pre-ART follow-up for children and adults ART, preventive services for HIV patients including provider initiated family planning.

Baylor Clinics through teen clubs offer a unique intervention that caters for the needs of adolescents and young people who were born with HIV. The Teen Clubs cater for children as young as eight years who have been fully informed of their condition and who have their parents' permission to participate. These teens meet monthly and form informal

and formal support groups to discuss a number of issues ranging from disclosure, adherence, Sexual and Reproductive Health, stigma, emotional health and Life Skills (Baylor College of Medicine – Malawi, 2012). Despite this achievement Baylor College of Medicine – Malawi (2012) acknowledges that SRH care still remains a challenge, it is one of the most underserved area for adolescents with HIV, teens have difficulty accessing SRH services due to lack of truly adolescent friendly staff, stigma, unwelcoming clinical situations, lack of provider initiated family planning services and modesty or embarrassment. Service providers seem not to be prepared to find out whether these clients are sexually active. Thus, SRH issues are not given due attention, which often leaves sexually active HIV-positive adolescents unable to negotiate contraceptive use or even to access contraceptive methods (Baylor College of Medicine – Malawi, 2012). In addition, information from Baylor-Lilongwe indicates that services like Antenatal clinics are not done at the facility, thereby negatively affecting the adolescent's access to prevention of mother to child transmission guideline and services in case of pregnancy.

WHO suggests that to effectively address the needs of adolescents, appropriate approaches are required because their needs are different from those of small children and adults (Marmot et al., 2008). However, in Malawi, HIV management services are traditionally separated into paediatric and adult care, which overlooks the unique needs of adolescents (Mwalabu, 2014). In addition, empirical data (WHO & UNICEF, 2008) reveals that apart from HIV teen clubs there are no specific SRH services targeted towards individual SRH needs within HIV management strategy to promote optimal SRH outcomes, in spite of the Malawi National SRH Rights defining rights as a key component of the national health strategy (Ministry of Health, 2009). Overall, despite great developments over the past decade, HIV management strategies and policies in Malawi

remain inadequate, particularly because they do not explicitly address the unique needs of young people specifically those infected perinatally and who have grown up to adolescence and young adulthood (Mwalabu, 2014).

Likewise, HIV services in other developing countries are often ill-equipped to address the specific needs of HIV-positive adolescents due to lack of consistent, age appropriate support regarding sexuality, relationships and transitioning to adulthood (Hodgson et al., 2012). Hodgson et al. in their study looking at psychosocial, SRH needs of adolescents aged 10-19 years living with HIV in Zambia, identified gaps between these needs and the existing services. Findings indicate that social network plays a great deal in their lives as they are determined not to allow HIV to change their lives. They would also want to know more on SRH and HIV information and access services which are tailored around HIV and SRH (Hodgson et al., 2012).

Adolescents living with HIV require effective, targeted and sustainable HIV services to navigate safely through adolescence (Hodgson et al. 2012). WHO/UNFPA guidelines on care, treatment and support for adolescents living with HIV/AIDS in resource-constrained settings have underscored the need to address this particular sexual and reproductive health need of adolescents with HIV, ensuring the availability of age-appropriate information and counseling on sexual and reproductive health, safer sexual practices, offering family planning counseling and services that are adolescent-friendly (WHO, 2006). Therefore, the current research used in-depth interviews to explore reproductive health needs and complex experiences in sexuality of this emerging group of young women and the risk they pose to others as they grow up with HIV, to inform policy and health practice and to promote best possible SRH outcomes.

## **Problem Statement**

Lack of comprehensive reproductive health service provision is of concern, with approximately 8.3% of PLHIV being denied family planning or sexual health services in most health facilities in Malawi (Malawi National HIV and AIDS Strategic Plan 2011 – 2016). And yet current data indicate high prevalence of unintended pregnancy which is at 35% (NSO, 2011) in the general population. In addition, adolescents in Malawi constitute more than one-fifth of the population; sexual activity in the general female population of adolescents begins early, with 14% of them aged 15-19 years having had sexual intercourse before 15 years (NSO, 2011).

Information gathered from Baylor Clinic in Lilongwe indicates that there is no policy to guide provision of integrated reproductive health services. Therefore, due to weakness of health care systems in general, reproductive health services in most cases do not adequately meet the needs of adolescents. The non-availability of antenatal services at Baylor clinic and absence of a policy, hampers the provision of an open and safe environment for ALHIV to talk about reproductive health needs, family planning, sex and sexuality, this increases their likelihood not to disclose pregnancies and hence not access preventing mother to child transmission (PMTCT) guidelines and services. However, it is not known whether ARVs have improved the desire for reproductive health and to engage in romantic relationship and childbearing in adolescents with perinatally acquired HIV in Malawi, given the circumstances in which they acquired the infection. So far no data is available indicating the reproductive health needs and sexual practices of adolescents with perinatally acquired HIV in Malawi. The available data is for adolescents in the general population and the adult population of PLHIV, hence the necessity for a study to explore

reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV.

### **Purpose of the study**

The purpose of the study is to explore reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV.

### **Specific Objectives**

The specific objectives are to:

- Identify reproductive needs of female adolescent with perinatally acquired HIV.
- Assess contraceptive knowledge, access and use among female adolescents with perinatally acquired HIV.
- Assess sexual practices of female adolescents with perinatally acquired HIV.

### **Significance of the Study**

Knowledge of reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV might help identification of better methods for provision of SRH services. The impact areas will be in management, education and clinical practice. In management, the findings would help policy makers to come up with policies in their planning and implementation of HIV and AIDS programs which are tailor-made, such as infrastructure and to conduct trainings for health personnel in SRH, so that they have knowledge on how to handle adolescents with perinatally acquired HIV. In the training institutions, issues of SRH shall be added to the curriculum so that student nurses are taught in advance on how to handle adolescents with HIV. In practice, SRH information

obtained shall add to the body of knowledge on how to promote SRH services for HIV positive adolescents in Malawi and other countries.

## **CHAPTER: 2**

### **LITERATURE REVIEW**

#### **Introduction**

This section on literature review has focused on studies that investigated reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV. Specifically, the review covers reproductive needs, pregnancy and marriage aspirations, contraceptive knowledge, access and use, and sexual practices. The key search terms and parameters used are; sexual reproductive health, needs, sexual behavior, adolescents and perinatally acquired HIV. A comprehensive literature search was done through various academic databases (MEDLINE, CINAHL, EBSCOHOST, HINARI) in order to review what is known about findings of recent existing studies on Reproductive Health Needs and Sexual Practices of Adolescents with perinatally acquired HIV and other related information. In absence of a conceptual framework, literature review was guided by the study objectives. As such literature review includes information and findings of previous research studies focusing on reproductive needs, pregnancy aspirations, knowledge, access and use of contraceptives, and sexual practices of female adolescents with perinatally acquired HIV worldwide; Malawi inclusive. Finally, the chapter concludes by revealing key gaps in the literature from which the research aims and objectives have emerged.

HIV is a disorder with a prolonged progression that can be fatal or associated with a comparatively normal life despite the compromised physical functioning (Scandlyn, 2000).

Therefore, adolescents with perinatally acquired HIV encounter a set of, social, sexual and psychological issues that need to be clearly addressed, it is during adolescence that young people often may struggle with behavioural experimentation, risk-taking, assertion for independence and personal identity (Battles & Weiner, 2002).

### **Reproductive Needs**

Adolescence is a period of emerging sexual desires, behaviours and relationships (WHO, 2008). These are a normal part of development, and when access to information and services is prioritized, they make healthy decision when supported and these can form the basis of lifelong sexual health and overall well-being (Woog et al., 2015). However, adolescents can be at high risk of adverse sexual and reproductive health outcomes, including unintended pregnancy, re-infection with HIV and other STIs (Shaw, 2009). Adolescents are also at elevated risk for poor health outcomes for themselves and their newborns should they give birth. Access to needed health information and services among adolescents is vital in helping prevent these outcomes and necessary for protecting the health of future generations (Shaw, 2009). Adolescents have a widely recognized right to accurate and comprehensive reproductive health information, education and services, yet too little is being done to help adolescents fulfill this right and obtain the sexual and reproductive health services they need (Jejeebhoy., Zavier, & Santhya, 2013).

According to Bakeera-Kitaka et al. (2007), the findings of the study in Uganda indicate that adolescents have limited information on how to adopt safer sexual behaviour, the study suggested that family planning - including discussions of effective and emergency contraception, pregnancy intentions, access and safer conception methods –

alongside with HIV prevention education - is needed in the primary HIV care setting. This type of comprehensive care can be achieved through a multidisciplinary awareness of the unique health needs of adolescents with HIV (Bakeera-Kitaka et al., 2007). There is need to seriously discuss adolescents' sexual desires openly and acceptingly; otherwise, adolescents may not receive necessary information and skills for adopting safer sexual behaviour. In general, adolescents living with HIV still seem to have far too little knowledge of emergency contraception. Similar findings are documented, in South Africa, where contraceptive prevalence is quite high compared to many other African countries, qualitative studies conducted among HIV and PMTCT clinic attendees showed that women living with HIV had little knowledge of emergency contraception or how to access it (Cooper et al., 2006).

According to Zorrilla et al. (2003), adolescents living with HIV, have reproductive health and sexual needs, despite their HIV positive status, they desire to love and to be loved and have plans to produce children. Zorrilla et al. (2003) in a study done in South Africa acknowledges the fact that adolescents are at liberty to choose when to engage in reproduction and sexual matters, marriage and access sexual health information and comprehensive sexual health services. Laher et al. (2009), alludes to the fact that the increased availability of antiretroviral treatment (ART) has been found to have a positive impact on future fertility intentions of HIV-positive individuals. Hence, it should be expected that births to HIV-positive women in such situations are likely to be intended.

As children living with HIV advance into adolescence, their focus on developing effective relationships becomes paramount (International HIV/AIDS Alliance, 2011). However, healthcare providers and society at large often assume that a person diagnosed

with HIV will not want to have a sexual partner, or should not have children (Fielden et al., 2006); service providers often forget that ALHIV are sexually active and that young women living with HIV may want to become pregnant. In a survey of youths aged 13–24 with perinatally acquired HIV, 70% expressed intent to have children (Ezeanolue et al., 2006). This clearly indicates the aspiration of adolescents born with HIV to one day have a family of their own.

Birungi et al. (2007) in a study in Uganda reported that most adolescents living with HIV dream of getting married and having families of their own. However, in this study several key informants acknowledged that counsellors advise HIV-infected persons to avoid getting pregnant but the call is not heeded. For instance, 41% of the sexually active female adolescents had been pregnant and almost three-quarters (73 %) of them delivered healthy babies. Less than 20% of sexually active adolescent males reported having impregnated a girl, and for half of those who had done so their partners kept the pregnancy. The desire to have children and families is also shown by the fact that more than two-thirds (69 %) of the adolescents who already had children intend to have more in the future. Likewise, more than four-fifths (86 %) of those who did not have children intend to have them in future. This study is a clear indication that adolescents who are HIV positive would one day want to have children of their own despite the fears instilled in them, hence the need to guide these adolescents through this stage in order for them to make informed decisions.

According to Baryamutuma and Baingana (2011), fertility intentions and choices are central to every human being, and adolescents with perinatally acquired HIV are not any different. It is anticipated that as adolescents graduate into adulthood, some will initiate

childbearing, as literature reveals that not only are they planning to produce children, some have already initiated childbearing (Bakeera-Kitaka et al., 2008). However, reproductive health services in most parts of the region are not oriented towards adequately addressing the needs of adolescents partly because of weak health care systems and partly due to cultural disapproval of teenage sexuality (Wood & Jewkes, 2006).

Although there isn't much indication in the literature to show that adolescent pregnancies are planned or not, some studies indicate that many are unintended. For instance, a study of South African pregnant women attending a prevention of parent to child transmission (PPCT) clinic found that 84% of clients' pregnancies were unintended (Rochat et al., 2006). In many parts of sub-Saharan Africa, the majority of pregnancies among adolescents aged 19 years and below result from unplanned and unprotected sexual acts are therefore mostly unintended (Okereke, 2010). Similarly, there are reasons to suggest that unintended births might just be as common among HIV-infected adolescents as other young people in the sub-Saharan region. For instance, recent evidence shows no significant difference in the sexual behaviour and childbearing experiences and intentions of those who were infected with HIV at birth and know their sero-status and their counterparts in the general population (Obare & Birungi 2010).

In Cape Town South Africa, Cooper et al. (2009), in a study on reproductive health care needs of adolescents living with HIV, highlighted the need to develop or formulate guidelines and counseling protocols which could address contraceptive needs and fertility desires within the specific context of individuals and their intimate main partners' HIV status and within developing country constraints, because unintended pregnancies (unwanted or mistimed) in the general population are estimated to account for 14–80% of

all pregnancies in some countries. Unintended pregnancy is even more prevalent among adolescents growing up with HIV in the developed countries, 83% in a cohort of US adolescents (Koenig et al., 2007) and 81% in adolescents in the UK and Ireland (Kenny et al., 2012). However, in Malawi there seems to be a gap in information on prevalence of pregnancy in adolescents with perinatally acquired HIV. However, unplanned pregnancy has been reported among HIV-positive women in Malawi, South Africa, and Uganda (Hoffman et al., 2008). Similarly, NSO, (2011) indicates high prevalence of unintended pregnancy in the general population which is at 35%.

Literature has shown that, the prevalence of unintended pregnancy in uninfected women in general is similar to adolescent with HIV. For instance, Zorilla and colleagues in Puerto Rico examined the factors associated with sexual activity and pregnancy in 8 perinatally HIV-infected adolescents with a history of pregnancy and 8 non HIV infected older females with a history of pregnancy (Zorilla et al., 2006). Findings suggest that the sexual behaviour and the prevalence of unplanned pregnancy of perinatally infected females' adolescents is similar to that of HIV negative women; hence the need to reinforce and prioritize sexual health issues including family planning for adolescents with perinatally acquired HIV, even though the sample size was too small for generalization (Zorilla et al., 2006).

### **Contraceptive Knowledge**

According to Birungi et al. (2008), knowledge of contraceptive methods is high among adolescents with HIV. A study in Uganda found that 84% of the study female respondents knew of at least one contraceptive method. The condom was the most known

method, followed by the contraceptive pill (Birungi et al., 2008). It has been acknowledged that despite the high knowledge of contraceptives among adolescents with HIV, there seems to be a gap between knowledge of ways of prevention and actual preventive practices. According to Rongkavilit et al. (2007) adolescents with perinatally acquired HIV rarely use protection such as condoms. It is evident that sexual practices of these adolescents are as risky as those who were born HIV negative (Baryamutuma & Baingana 2011).

### **Contraceptive Access**

According to UNAIDS (2010), many adolescents who know their HIV status fail to access health services in reproductive health. Malawi Net for HIV positive attributes this to fear of stigma or lack of information. MANET+ (2003), explored factors that affect young people living with HIV; findings indicate that lack of information, stigma and discrimination were key factors with significant influence on the ability of adolescent living with HIV to live positively with their status. Such negative experiences could be a barrier to HIV reproductive health access. Nations including Malawi need to deal with such a negative experience which is a gateway to accessing health care and positive living with the infection.

In sub-Saharan Africa, recent qualitative studies exploring adolescents' experience of living with HIV, have shown vertically-infected adolescents to be ill at ease in discussing sexuality due to fear of stigma, preoccupied with secrecy around HIV (Li et al., 2010; Hodgson et al., 2012; Birungi et al., 2009). As such, a study of perinatally infected youth in South Africa, ages 12–24 demonstrated limited knowledge of safe sex, as 41% were sexually active (Wiener et al., 2007).

## **Contraceptive Use**

In a cohort of Ugandan youths started on antiretroviral therapy (ART), there also exists a high unmet need for contraception, for instance 17% became pregnant over the 2-year follow-up period, despite 93% not wanting or planning a pregnancy (Homsy et al., 2009). Additionally, among the female youths who did not desire children, only 14% were using a modern contraceptive method other than condoms (Homsy et al., 2009).

However, study findings on the use of contraception among HIV positive youths are mixed, a recent study in Uganda showed HIV positive adolescents more likely to use contraception, particularly condoms, than those who were either HIV-negative or unaware of their status (Beyeza-Kashesya et al., 2011). The study indicates that 49.6% HIV positive adolescents aged between 15–19 years reported ever-use of contraception and 39.3% were currently using condoms. Meanwhile among those who did not know their status, only 17.0% had used contraception and 11.1% were using condoms (Beyeza-Kashesya et al., 2011).

In Bangkok, Thailand, a qualitative study involving 70 HIV-positive youths between 16 and 25 years of age, regarding risky sexual behaviour; found that almost half of the participants practiced inconsistent condom use (Rongkavilit et al., 2007). Hence the need for targeted sexual and reproductive health intervention programs for adolescents living with HIV, the study concluded. In Malawi reproductive health needs and sexual practices have rarely been the focus of investigations in perinatally acquired HIV adolescents; as such little is known about contraceptive use in this group. Instead unmet need for contraception and sexual practices have been addressed by studies in adults and

the general population of adolescents, leaving a gap in information regarding reproductive health needs and sexual practices of adolescents with perinatally acquired HIV.

### **Sexual Practices**

In Canada, a study on romantic relationships and sexual activity of this first generation of adolescents living with HIV revealed that these young people start having unprotected sexual relationships at an average age of 14 for girls and 15 for boys (Fernet et al., 2011). The findings are consistent with a study in America which proved that adolescents with perinatally acquired HIV are engaging in sexual activities as early as 14 for girls and 15 for boys (Fernet et al., 2011).

According to a study in the USA; after the advent of highly active antiretroviral therapy, study findings demonstrated that HIV positive youths aged 13-24 were more likely to have unprotected sex with a partner whom they knew was also HIV positive (Rice, Batterha & Rotherram-Borus, 2006). This is an indication that HIV positive adolescents like to associate themselves with their counterpart who are HIV positive. However, this finding is not consistent with Birungi et al. (2009) who reported in their study that many of the HIV positive adolescents prefer HIV-negative partners. Another study with 156 HIV-positive adolescents (13 to 21 years old), infected perinatally in the United States, showed that close to 2/3 of the participants were sexually experienced and approximately half of them had engaged in unprotected sexual practices since becoming aware of the diagnosis (Koenig et al., 2009). The author rightly concludes that the risky sexual behaviour of perinatally infected adolescents is greater than previously estimated and points to the need of appropriate educational tools for early guidance in sexuality and health of these young people.

Similarly, Bakeera-Kitaka et al. (2008), in a study which looked at sexual risk reduction needs of adolescents living with HIV in a clinical care setting, with a study population of adolescents attending the Pediatric Infectious Disease Institute (PIDC) who knew their HIV status; 75 HIV infected adolescents participated in the study, thirty-five (46.7%) of them were female. The age range was 11-21 years, with a mean and median age of 16 years. The study reviewed that about a quarter of the study participants reported to have experienced sexual intercourse, adolescence in itself was perceived as a time of sexual experimenting and having to deal with peer influence. Peer pressure was reported as a main barrier to protection. Young people living with HIV (YPLH) desired to be like their friends who were already involved in sexual relationships (Bakeera-Kitaka et al., 2008).

However, Bauermeister et al. (2009) in a study comparing sexual behaviours of perinatally HIV-infected (PHIV) and non- HIV affected youth aged 9-16 years, explored the prevalence of sexual behaviours that is; kissing, touching and engaging in sexual intercourse, they tested the association between sexual behaviour and HIV status, and peer influences regarding sexual behaviour. Findings indicated that PHIV youth were less likely to be sexually active, but both groups were greatly affected by peer norms. Among sexually active youth, PHIV youth were more likely to engage in touching behaviour than HIV-negative youth. They were also less likely to engage in penetrative sex (Bauermeister et al., 2009). In another study Birungi et al. (2009), examined sexual behaviour and desires among adolescents perinatally infected with Human Immunodeficiency Virus in Uganda and the implications for programming. The study involved both survey and qualitative interviews with perinatally HIV-infected girls and boys aged 15–19 years. A total of 740 young girls and boys were identified for the survey and 732 were successfully interviewed. Female respondents comprised about two-thirds (64%) of the study sample. A wide range

of issues were covered among other things; access to sexual and reproductive health information, sexual behaviour, preventive knowledge and practices, contraceptive knowledge and use, pregnancy and childbearing intentions and experiences, Findings indicated that these adolescents are beginning or do desire to explore their sexuality. Of all interviewed, 44% reported a desire to have sex, and 41% believed that there was no reason why someone living with HIV should not have sexual intercourse. 33% of the respondents reported having had sexual intercourse. It was noted that of those who had had sex 73% had consensual first sex.

Anecdotal evidence from The Aids Support Organization (TASO) in Uganda and from South Africa suggests that most HIV-positive adolescents are likely to seek sexual relationships, and have unprotected sex, with other HIV-positive young adults (Birungi et al., 2008b). This is an indication that ALHIV are engaging in risky sexual activities and yet according to the findings there are gaps in addressing sexual and reproductive health needs of the young people who have lived with HIV since infancy. In Malawi where adolescents constitute more than one-fifth of the population; sexual activity in the general population of adolescents begins early, with 14% of girls and 26% of boys aged 15-19 years having had sexual intercourse before 15 years (NSO, 2011) and 65% being sexually active before 18 years (Munthali et al., 2006). However, there is information gap regarding reproductive needs and sexual practice of adolescents born with HIV. The available data is for adolescents in the general population and the adult population of PLHIV, hence the necessity for a study to explore reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV, in order to inform policy to formulate tailor made reproductive health services.

## **Conclusion**

It is rightly documented that adolescents with perinatally acquired HIV have the freedom of choice regarding reproduction, sexual matters, marriage and the fundamental right to access sexual health information and comprehensive sexual health services. However, they are one of the subgroups that are not well attended to in terms of reproductive health service provision. Literature has shown that for Young People with perinatally acquired HIV, the challenges of adolescence are made even more complex considering the relationship between sexual activity and HIV transmission. Despite their HIV positive status, they have sexual and reproductive health needs and right to information on such matters.

## **CHAPTER: 3**

### **METHODOLOGY**

#### **Introduction**

This chapter describes the approach, which was taken to explore reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV. The chapter describes the study design, setting, population, sample and sampling method, recruitment process, data collection techniques, data analysis, ethical consideration and study limitations.

#### **Study Design**

An exploratory research, utilizing qualitative data collection approach was conducted in Lilongwe city targeting adolescents with perinatally acquired HIV attending ARV clinic. The design was deemed appropriate for this study because there is limited information regarding reproductive health needs and an inquiry into the sexual practices of female adolescents with perinatally acquired HIV. A qualitative approach helps to obtain a better understanding of human behaviour, attitudes and practices, opinions or views and feelings of the participants in the context in which the action takes place and gives them meaning (Brink, 2010). This approach uses detailed descriptions from the perspective of the research participants themselves, as a means of examining specific issues and problem under study (Brink, 2010). The advantage of this approach is that the researcher can probe into adolescents' ideas, practices and feelings more deeply. It is also meant to answer some of the complex questions that quantitative methods may not be able to unravel. In addition,

qualitative interviews are fairly informal and participants feel they are taking part in the conversation or discussion, than in a formal question and answer situation and illiterate participants would be able to give in their input that cannot be achieved with self-administered questionnaires, similarly researcher administered questionnaire is a quantitative method mostly employed in a survey. Therefore, qualitative interviews capture verbal and non-verbal cues including body language, which can indicate a level of discomfort with the questions. Adversely, it can also indicate a level of enthusiasm for the topics being discussed in the interview.

### **Study Settings**

Data collection was done at Baylor College of Medicine International Pediatric AIDS Initiative at Texas Children's Hospital – Malawi (BIPAI). It is the largest provider of paediatric HIV care, treatment and support for over 4,500 HIV infected or exposed infants, children, adolescents and youth. This site is situated at Baylor College of Medicine Children's Foundation-Malawi clinic in Lilongwe, the central region of Malawi. Data from the centre indicate that in 2013 a total of 2, 064 children were registered for HIV care service; of these 527 were adolescents aged 13-20 years. Out of this figure there are 56 clients aged 17-18 years, 71 clients aged 18-19 years and 39 clients aged 19-20 years. The site has been selected because it is the only largest provider of Paediatric HIV in Lilongwe city. In addition, so far no similar study has been done at the facility.

### **Study Population**

The study population includes female adolescents aged 18-19 years old, attending HIV clinic, with perinatally acquired HIV and have disclosed their own HIV status. This group has been selected because they are in the late adolescence stage and are emerging

adults planning for the future, and can consent without seeking parental permission, as would be the case with minors, since the minimum age for individual consent in Malawi is 18 years (Malawi Demographic Health Survey, 2004).

### **Sample**

According to (Burns and Groove, 2009) data saturation determines the sample size adequacy. This meant that the sample size would increase or decrease depending on data saturation. Saturation of data occurs when additional sampling provides no new information but only redundancy of previous collected data (Burns and Groove, 2009). In this study a sample size of 16 female adolescents born with HIV was pre-determined to be interviewed. The participants were interviewed with close observation on data saturation. After data saturation an estimated total of 10 female adolescents with perinatally acquired HIV was interviewed based on age (5 from each age group 18 and 19), at this point no new information emerged.

### **Sampling Method**

Purposive, sampling also known as judgmental was used to select female adolescent participants for in-depth interviews. It is a sampling method in which elements are chosen, based on the purpose of the study (Burn & Grove, 2009). In this strategic approach participants were selected according to their characteristics (Brink, 2010), for instance one of the inclusion criteria are female HIV positives, who have declared their HIV status; these adolescents shed light on their reproductive health needs and sexual practices.

### **The Inclusion Criteria**

The participants in this study included female adolescents

- Aged 18-19 years, married or not, attending Paediatrics ARV clinic and residing in Lilongwe for easy access.
- Those with perinatally acquired HIV and have disclosed their own HIV status, because they are more likely to freely talk about their inner feelings and practices.
- Those who had joined the teen club for easy sampling
- Those with the capacity to provide written consent
- Willing to have individual in-depth interviews recorded
- Able to communicate in Chichewa or English

### **The Exclusion Criteria**

- The exclusion criteria included female adolescents:
- Who had not disclosed their own HIV status so that their privacy to information is maintained
- Those who had not joined the teen club
- Younger than 18 years old because they would need parental consent and those above 19 years.
- Not willing to participate in the study.
- Not able to communicate in Chichewa or English.

## **Recruitment Process**

After getting approval from COMREC, the researcher approached management of Baylor College of Medicine Children's Foundation – Malawi, in Lilongwe, and an explanation was given about the study, its purpose, objectives, and all the planned activities. As a requirement for Baylor a National Institutes of Health Web based training course on “Protecting Human Research Participants” (Appendix H), was done by the researcher before conducting the study. Verbal and written permission was sought with an intention of consciously selecting participants with emphasis on variation of characteristics within the agreed upon inclusion criteria. Thereafter the researcher held meetings with service providers/counselors who work with the adolescents. The objective of the meetings was to introduce the study and its procedures to the providers, and to request them to identify, mobilize, and link willing participants with the researcher after explaining to them the purpose of the study.

The researcher then identified potential participants attending the clinic on each particular day, and invited each client to participate in the study. After each participant granted permission and was comfortable enough, a request to participate was extended through provision of the client information sheet (Appendix A), which also contains information on the purpose of the study.

Considering the sensitive nature of the study (HIV), the interviews were conducted in the private room at Baylor College of Medicine Children's Foundation-Malawi clinic in Lilongwe, on different days agreed upon together with individual participants. This method helped to gain access to female adolescents who are difficult to find. It is also considered appropriate because recruitment is on a voluntary basis (Polit & Beck, 2010).

## **Data Collection**

The study collected information through individual in-depth interviews. A semi-structured interview guide was used to initiate and guide the interviews, which was carried out in Chichewa, the national local language of Malawi (Appendix F), by the principal investigator. The semi- structured interviews are sometimes also called focused interviews. They consist of series of open ended questions based on the topic areas the researcher wants to cover, which define the topic under investigation but provide an opportunity for both the interviewer and interviewee to discuss some topics in more detail (Polit & Beck, 2010). This method gave the researcher the freedom to probe the interviewee to elaborate or follow a new line of inquiry, introduced by what the interviewee said. As such there was no research instruments developed. However, based on key SRH areas that were identified in the literature review, are to be addressed in the broader framework of rights and SRH services for HIV-positive adolescents. The interview guide was open-ended and included probes for potential additional issues (Appendix E and F) that could emerge as important concerns among the participants. The researcher helped the participants to describe their practices without leading the discussion (Polit & Beck, 2010).

The in-depth interviews lasted 60-90 minutes and were conducted at the selected centre. In addition, the individual in-depth interviews were tape recorded in a few of the participants after gaining permission from them. In the majority of the participants' tape recording was not done as they felt insecure and breach of confidentiality despite assurance from the researcher. In a few who accepted, tape recording was done to ensure accurate data and to facilitate analysis. Field notes were intensified and were taken to complement the findings on tape; these were taken in order to record any observations such as tone of voice, facial expression or where participants did not want to be taped. Data was collected

until there was data saturation, when no new information was obtained (Polit & Beck, 2006).

The purpose of the individual in-depth interviews was to gain an understanding of what was going on in the life and minds of the participants, in this case adolescents with perinatally acquired HIV, their needs in reproductive health, their sexual practices knowledge levels and use of contraceptives and recall as well as to gather factual information (Brink, 2010). After the first interview, the researcher transcribed and analyzed the collected data in order to determine if the individual in-depth interview questions would bring out the desired information. It would also be for estimating how long it would take to complete each interview and to identify any ambiguities that needed modifications. This data formed part of the report.

Selected socio-demographic data were collected on all participants, including age. Additional information such as marital status, number of living children, religion and educational level was also collected. Socio-demographic data were linked to responses from audio tapes using a coding system, eliminating the use of individual names as a measure of confidentiality protection.

### **Data Management**

Qualitative in-depth interviews were recorded on tapes in some of the participants and simultaneously recorded in writing. The interviews were transcribed verbatim and comparison with written notes was done for completeness, accuracy and as a quality assurance measure. Each typed transcript was checked against the audiotape by the researcher before being translated into English sooner than later. Ulin, Robinson, Trolley and McNeill (2005) suggests that audiotapes should be transcribed as early as possible in

order not to miss subtle, non-verbal points and give timely opportunity for the researcher to clarify ambiguities, investigate new leads and follow-up emerging issues.

Safety was observed for the collected data, the researcher assigned identification codes to all individual records including files, transcripts and any other data. Documents were then stored in an organized manner by carefully recording dates when the data was collected, organizing and coding on note cards and this was filed and kept under lock and key, accessed only by the researcher. After data analysis, all used notes were destroyed by burning them. This helped to ensure confidentiality.

### **Data Analysis**

Data was analyzed manually by thematic analysis; transcripts were coded inductively to create a coding scheme and emerging themes generated (Stemler, 2001). The purpose of thematic analysis was to identify patterns of meaning that provided an answer to the reproductive health needs and sexual practices of adolescents with perinatally acquired HIV. Thematic analysis is performed through the process of coding in six phases to create established, meaningful patterns. These phases were identified through a vigorous process of familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report (Ulin et al., 2005).

For data integrity, some of the interviews were audio recorded and transcribed. Not all of the participants agreed to be recorded citing issues of confidentiality, however, each session was transcribed using the original language (Chichewa). Oliver, Serovich, & Mason (2005) encourage maintaining of the original language of the interview during transcription as critical for the analysis of qualitative data in order to safeguard the integrity

of the research findings. The original language was used to complete the coding of the transcripts of the interview. Selected passages from the interviews after the analysis, were translated into English these are included in the text of this article. The translations were completed by an independent translator. All the translations were checked and edited for accuracy by the researcher.

### **Phases of Thematic Data Analysis**

**Familiarization with data.** The researcher read the transcripts and field notes carefully and repeatedly, 'immersing' herself in the data (Lavender, Edwards, & Alfirevic, 2004), to familiarize herself with its content. Reading for content, asking questions, noting quality and identifying patterns from the very first transcript. After the first interview, field notes were re-read and the tape recorder was listened to, while asking if the objective was addressed.

Data was read for content to establish whether the researcher was getting what was intended to be collected, and recognized that the first data may not have been as rich as desired. In some instances, the questions were not framed adequately, hence the responses did not address the research questions. This was a chance to rephrase questions in a manner that yielded better outcomes. Data was then read to note quality, including determining whether responses appeared credible with sufficient contextual detail. Credibility of data was determined at this stage.

**Coding.** This phase began when you have read and familiarised yourself with the data, and have generated an initial list of ideas about what is in the data and what is

interesting about them. This phase then involves the production of initial codes from the data. Codes identify a feature of the data (semantic content or latent) that appears interesting to the analyst and data that might be relevant to answering the research question. It involved coding the entire data set, and after that collating all codes and all relevant data extracts together for later stages of analysis. Highlighters were used to group the identified statements or phrases. For example under the first objective relating to health needs, participants were asked what knowledge they had regarding reproductive health services available; the revisions they desired and the reproductive health services they would desire added to the existing ones, majority of the participants expressed ignorance on other reproductive options apart from injectable, they wish was to access comprehensive health information during each visit, they also wished to receive education on different types of contraception and other reproductive guidelines. As such all information relating to a particular code was highlighted in the transcript in a particular colour as a means of organizing the data. Then the different colours were used to identify and organize statements with similar meanings in order to group them and later to develop themes from them.

**Searching for Themes** this phase involved examining the codes and collated data, to identify significant broader pattern of weaving (potential themes). The researcher collated all the coded data from phase two and named the selected text within each data item according to colours and giving each meaning by describing. Themes ranged from quick word counts to laborious, in-depth, line-by-line scrutiny, looking at the used words which are repeated, and noted synonyms which were used a lot. The researcher combed through the recorded material and notes looking for verbatim statements made by informants regarding each objective. Each time a word was found a copy was made and its

immediate context. For instance, under objective reproductive health needs; “desire for children” was mentioned by the majority of the participants. The participants highly valued fertility, as the majority of the girls indicated that they would want to have children whether or not they were HIV positive, however, almost all of the participants expressed a strong desire to have children in the “future”. These themes were identified by physically sorting the examples into piles of similar meaning. Each line or sentence was read and the researcher asked herself "What is this about?" and "How does it differ from the preceding or following statement

**Data reduction.** This was a process of distilling the information to make visible the most essential concepts and relationships, which often happened once all the data had been read, coded and displayed (Ulin et al., 2005). Data reduction involved stepping back from the data to get an overall sense of data and establish main and secondary themes. At this stage data was reduced to classes or categories in which the researcher was able to identify segments of the data that share a common category or code. This was done by noticing relevant phenomena, collecting examples of the phenomena, and analyzing the similarities, differences, patterns and overlying structures (Braun & Clarke, 2006).

**Interpretation.** Defining and naming themes. This phase involved developing a detailed analysis of each theme, working out the scope and focus of each theme, determining or deciding on informative name for each theme.

**Writing up.** Final phase, involved weaving together the analytic narrative and data extracts and contextualizing the analysis in relation to existing literature.

## **Strategies to enhance trustworthiness of the approach**

Trustworthiness described as the “methodological soundness and adequacy” (Holloway & Wheeler, 2010:302), is judged through the constructs of credibility, dependability, transferability and confirmability. In qualitative research, it is also accepted that research should be evaluated critically and justified in order to ensure that the study is done in an honest manner, to meet the academic requirements. According to Brink (2010) qualitative data is assessed for trustworthiness or true value. In this study, trustworthiness was achieved through ensuring credibility, dependability, transferability and confirmability as these define for external audience the attention qualitative researchers render to their work (Polit & Beck, 2008).

### **Credibility**

Credibility refers to confidence in truth of data and its interpretation (Polit and Beck, 2008). This involves two aspects: first, carrying out a study in a way that enhances the believability of findings. Secondly taking steps to demonstrate credibility to external readers, this is done through prolonged engagement with participants in a given subject matter to get a deeper and complex understanding of adolescent’s reproductive health needs and practices. Therefore, sufficient time was dedicated for data collection activities. This helped to have individual in-depth understanding of the views as they unfolded naturally. In this research, probing was very instrumental in obtaining as much truth from participant statements, to establish any underlying information and nuances as well as obtains a more in-depth perspective.

The researcher also built trust and rapport with participants. Developing a trusting relationship with the research participants also helps to yield credible data. This was

achieved by maintaining contacts with research participants. Members who participated in the study were provided with feedback on the emerging themes and seek clarification where necessary in order to have a true reflection of their views. Confidentiality was maintained and unintended disclosure avoided. Credibility was enhanced by keeping notes throughout the data collection period and during data analysis.

### **Dependability**

Dependability refers to stability or reliability of data over time and over conditions (Polit & Beck, 2010). This was done by answering the question of “would the findings of the inquiry be repeated if it were replicated with the same similar participants in the same or similar context”? This was achieved by keeping detailed records of the research process. This would enable future researchers to repeat the study, in the same context, with the same methods and participants, and obtain similar results. In this research, an audit trail enquiry was used, meaning that audit and decision trail where readers can trace the data to their sources. An audit enquiry scrutiny of relevant documents assessed the extent to which proper research practices have been followed. This record enables the researcher and others to track the process that has led to the conclusions which is created from notes and other field material (Polit & Beck, 2010).

### **Transferability**

Transferability essentially refers to the generalizability of the data, that is, the extent to which the findings could be transferred to or the applicability in other settings or groups. This can be achieved by providing sufficient descriptive data to other similar context (Polit & Beck, 2008). The researcher was able to achieve this by producing a detailed description of the methods used in data collection, analysis, as well as the setting where the study took

place. This would enable another researcher to apply the findings to another setting and come up with similar results.

### **Confirmability**

Confirmability denotes the extent to which the research findings could be confirmed or verified by others (Lincoln & Guba, 1985). Lincoln and Guba demand confirmability, as an audit and decision trail where readers can trace the data to their sources. This includes transparency of how the sample was chosen in this case purposive sampling, the research methods used and explicitness on how the researcher arrived at the themes and their interpretations. As such, the researcher in the current study documented the procedures for checking and re-checking the data throughout the study. Similarly, in this thesis, the researcher has provided a clear account (step-by step) of the actual procedures used for access and recruitment of research participants, data collection and analysis.

### **Ethical considerations**

Ethical considerations include protecting confidentiality and anonymity of the participants on publication and in the use of the findings. It also includes the responsibility of offering participants a chance to hear about the findings of the study (Pera & Van Tonder, 2005). Hence, in this study the proposal was submitted to College of Medicine Research and Ethics Committee (COMREC) in Malawi for approval and permission to conduct the study (Appendix H), and the management of Baylor in Lilongwe (Appendix G), where the study was to be conducted.

Essential principles underlying the protection of human subjects are the principles of respect, beneficence and justice (Polit & Beck, 2006). In order to conduct the research in an ethical manner, these principles were adhered to throughout the study by allowing the participants to withdraw from the study if need arises with no consequences and maintaining confidentiality through use of numbers instead of names. In addition, the following was done to ensure that the study complied with ethical requirement of every research: The participants were informed of the study by the researcher and an invitation to participate was extended. Information sheets about the study, purpose, and significance were read and given to participants to allow them to make an informed decision about their participation in the study, both English and Chichewa (Appendix A and B respectively).

After the participants agreed to participate in the study, they signed a written consent form (Appendix C). This was kept by the researcher under lock and key to ensure that participants remained only known to her. Participation in the study was voluntary; refusal to participate did not affect the standard of care rendered in clinical care. They were informed that they are at liberty to withdraw from taking part in the research at any time. One of the participants withdrew from the study, she felt uncomfortable being interviewed. Information about the participants was kept confidentially, as only the person involved in the study had access to it. Individual in-depth interviews were conducted in private rooms at the clinic. Anonymity was maintained by the allocation of numbers for each participant, instead of using their real names. The risks associated with participating in the study, such as emotional upsets, were kept minimal. In the event of an emotional breakdown during individual in-depth interviews, the researcher attended to such clients since she is a trained HIV/AIDS counselor. No information was collected that does not relate to the study.

## **CHAPTER: 4**

### **PRESENTATION OF FINDINGS**

#### **Introduction**

This chapter presents results of an exploratory study utilizing qualitative methods, giving details of the participant's background information and the findings. Main themes have been presented in line with the purpose and objectives of the study. The major themes being presented are access to information and services, desire for children knowledge of contraceptives, access and use, sexual behaviour. Participants' feelings, views, thoughts, and ideas that were gathered through individual in-depth interviews from female adolescents living perinatally acquired HIV, have been highlighted.

#### **Demographic characteristics**

The study was conducted through in-depth interviews with 10 female adolescents with equal representation from each age group. The variables which were studied included age, level of education, religion, relationships and sexual behaviour. The study was conducted through in-depth interviews with 10 female adolescents with equal representation from each age 18 and 19 (n=5). All the adolescents attended school and the majority's current level of education is form 4, (n=4), followed by form 3 (n=3) and form 2 (n=20), only one female adolescent reached standard 8 and dropped out. All of the participants were Christians (n=9) except for one who was a Moslem. Almost all of the participants were in a relationship (n=7) the rest had no boyfriends. All, except three of the participants started their sexual debut before the age of 18 (n=7) of these (n=4) were sexually active at 15 years of age (Table 1).

**TABLE 1: Demographic characteristics of participants (n=10)**

Characteristics	number of participants (n)
Age of participants in years	(n)
18	5
19	5
Education	(n)
Primary (grade 8)	1
Secondary (form 2)	2
Secondary (form 3)	4
Secondary (form 4)	3
Religion	(n)
Christian	9
Islam	1
Current relationship status	(n)
In a relationship	7
No boyfriend	3
# of children	(n)
Pregnancy	none

Future plans	8
Sexual behaviour	(n)
(Age at first sexual debut)	
Before 18yrs	7
At 15	2
Use of condoms	2
Unprotected sex	2

### **Thematic content analysis**

The study was analysed using thematic analysis method. Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998). The following themes were identified which were guided by the study objectives.

### **Theme 1: Reproductive health needs**

#### **Access to information and services**

One of the study objectives was to identify reproductive health needs of female adolescents with perinatally acquired HIV. Participants were asked to describe the reproductive health services that were available at the facility. There was a wide spread ignorance on other reproductive options available and how to use them, participants wished to access comprehensive health information during each visit. They also wished to receive

education on different types of contraception and other reproductive guidelines; participants had no idea about other reproductive options; the excerpts below illustrate their experiences, their level of knowledge or awareness on reproductive option and guidelines available. When asked to explain the reproductive options and guidelines on HIV and their reproductive rights; none of them was sure of the existence of such a guideline and options, one participant had this to say. *“For specific reproductive options and guidelines on reproductive health, I honestly don’t know about them. What I have heard is something on infant feeding options, not reproductive rights”* (Participant # 5).

What was clear from the participants was the barrier they are faced with when accessing reproductive health services. participants pointed out negative attitudes from providers’ towards provision of reproductive healthcare, as such it was evident from the discussion that participants were discouraged to talk more about their sexuality due to how the service providers displayed themselves through unwelcoming facial expressions from the time they enter the service rooms, the provider’s attitude affects access to information (participant # 2) explained that *“Nurses... aaaah...the Malawian nurses I fail to ask; where will I start from, I don’t....may be its over work or what, the facial expressions they give you eee.... But the white doctors are very helpful unfortunately they don’t stay long.”*

Participants were further asked to explain the desired revisions in the current reproductive health services, and from the discussion misconceptions were evident with regard to the safety of hormonal contraceptive methods among adolescents on ART. Participants expressed their feeling as follows *“There is this method....mm...they say, a rubber it is put inside you, for me I can’t be on it, I feel it can hurt me it should not be given”* (Participant # 6). Supporting the same another participant explained; *“People talk*

*about... Mmm... that one they insert inside. I hear that it is dangerous. Is it true or not? I am asking because it seems that one might deliver a child with missing body parts”.*

(Participant # 2)

### **Desire for children**

Participants were also asked about their aspiration for children. There was an overwhelming desire for children as they were in romantic relationships. The findings have shown that being infected with HIV does not negate desires for children. Participants highly valued fertility, as they highly indicated that they would want to have children whether or not they were HIV positive. However, the study has revealed that the desire to have children was in the future. The desire to have children but in future is supported by this quote “*After my studies I would wish to get somebody who is aware of my HIV status. Besides, I also think about having children but I cannot have them except after I complete school*” (Participant # 4).

### **Theme 2: Contraceptive knowledge**

#### **Meaning of contraceptive method**

Knowledge on contraception was assessed. Participants were asked to discuss the meaning of contraception and explain its importance. Findings reveal an overwhelming understanding of contraceptive methods among adolescents. Participants were able to describe contraceptive as method to prevent unwanted pregnancy and to prevent STDs; Most of them knew the types of contraceptives. Overall respondents knew of at least three contraceptive methods; others were able to explain at least one method. The injectable type

was the most known and used contraceptive method. “*I know injection that is what I use, because it is secretive and I use it because I don’t want to get pregnant. My parents or boyfriend will not know that I am using any contraceptive method*” (Participant # 5).

### **Importance of contraceptive methods**

Importance of contraception was assessed. Participants explained that contraceptive methods protect them from unwanted pregnancies and other STIs. Findings showed a common concern amongst participants’ with regards getting pregnant, hence the reason for taking injectable form of contraception. Despite them having an idea about protection from unwanted pregnancies and STIs by using condoms, this knowledge did not translate into condom use, emphasis was on not getting pregnant only thereby exposing them to HIV re-infection and other STIs, and possibility of infecting others, one participant had this to say, “*Injections protect me from getting pregnant when I am not yet ready for it*” (Participant # 6).

### **Theme 3: Contraceptive access and use**

Participants were asked to explain on accessibility and utilization of contraceptive methods. According to the findings participants gave both positive and negative responses with regards to preferred type of family planning methods and its usage. Findings indicate that among the adolescents who reported using contraception, Depo-Provera (injectable) was the most commonly reported family planning method used. Adolescents reported that they prefer this method because it is easy to hide the use from their partners and parents. And what came out as striking information was that only condoms and injectable form of contraceptive was offered at Baylor thus frequently used. One participant lamented “*I use*

*Injection because it is secretive and it is readily available. My parents or boyfriend will not know that I am using any contraceptive method”* (Participant # 2).

While some of them used injectable form of contraceptive only, none of the respondents knew or have used dual contraception let alone an emergency contraception and yet participants reported at least one episode of unprotected sex in the last six months, while others were forced into unprotected sex. This is what one participant said” *I had sex with him three weeks ago, he forced me to have it plain without using a condom but I love him and I want to get married to him”* (Participant # 5).

All in all, adolescents were afraid of consequences of unwanted pregnancy and this could have been the reason why they got motivated to protect themselves. The respondent's feared dropping out of school, and rejection from parents. However, of the participants whose partners insisted on use of male condoms, hardly any shared the responsibility with their partners for ensuring that condoms were available before intercourse, they simply relied on their partners to do so.

### **Contraceptive method point of collection and access**

Participants were asked where they would collect contraception and why. Knowledge of where young people could obtain contraceptives and/or learn about contraceptives was wide spread. Respondents were also asked about where they would feel comfortable getting a contraceptive method if they wanted and why. Participants found it easy and confidential to access family planning methods from non-government facilities. Most of them preferred an HIV/AIDS site such as Baylor clinic, while some thought

services offered by Banja la Mtsogolo were more secretive and user friendly. One participant narrated "*I prefer sourcing contraceptives at Banja la mtsoglo, because they explain better, even I could stay in my marriage or relationship my boyfriend or family cannot know that am on family planning by the time they know it will be too late....giggles.... I already started*" (Participant #4).

### **Reason for non-usage of contraceptives**

Findings further showed that other participants were not using contraception. Although awareness of contraception was, use of a method was not. Various reasons were cited for non-usage of contraceptives by respondents, this difference between widespread knowledge and low use in other respondents could be due to a lack of information about or limited supplies of contraceptives, issues of age came out clearly, saying that contraceptives are not supposed to be used at their age. Furthermore, their fear was that contraceptive are not one hundred percent effective and it is also dangerous to health especially to the HIV positives. Although oral contraceptive pills are also popular, none of the adolescents use them; however, they don't know the reasons behind the health workers not offering them this type of contraceptive. Some of them heard health workers saying that pills cause damage to organs. It could also be due to prevailing misconceptions about other contraceptives. Some of the adolescents were not using any method of contraceptive to prevent pregnancy. The major reasons for not using family planning methods included partner refusal and lack of interest due to their HIV status and stigmatization by health workers. "*Ummm.....if I request for contraceptives..... these nurses will think that I am a prostitute*" (Participant # 7).

The findings further point to some level of inconsistent use of contraception as illustrated by the following quotes “*My boyfriend is resistant to condom use. He asks me why I always want to use a condom he says even protected sex is risky because there are accidents... like the condom can burst*” (Participant# 5).

#### **Theme 4: Sexual practices**

Participants in the study were asked to describe their sexual life. Findings demonstrated risky sexual behaviour; participants explained the reasons why they indulged in sexual activities and why others never indulged in sexual activities.

##### **Sexual behaviour**

The findings indicate that participants were engaged in risky sexual activities having intimate boyfriends; making them-selves unimmune to gender norms that sometimes make negotiating safe sex within intimate relations a risky undertaking. Findings indicate that participants are engaging in unprotected sex exposing themselves to HIV re-infection and other STIs. Further probing indicates an early sex debut, participants started having sex before the age of eighteen. Interestingly, findings indicate that some adolescents started having sex when they were 15 years old as illustrated by this quote “*I have one sexual partner.... We had sex twice this year and three days ago with no condom.... I started having sex when I was 15 years*” (Participant # 6)

##### **Reasons for indulging in sexual activities**

Findings show fear of losing the boyfriends to other girls and lack of trust as a basis for indulging in sexual activities; furthermore, findings indicate that participants indulged in sexual activities due to peer pressure. Adolescents explained that at times their partners

resisted condom use as such they fail to negotiate condom use for fear of losing their boyfriend to other girls (Participant no#5) explains “*I am currently having sex, if I refuse he asks me why and I am afraid he might go to another girl*”.

The participants indicate that even in the event of disclosure, the partners do not mind having sex or continuing the relationship even if they differ as demonstrated by the following excerpts “*I have a boyfriend. He knows my HIV sero-status. I disclosed to him and he said that he didn't mind*” (Participant # 8).

### **Reasons for not indulging in sexual activities**

The study findings indicate elements of fear in participants of the consequences of unwanted pregnancy were the strongest motivation for non-indulgence in sexual activities. The respondent's feared dropping out of school, rejection from parents if they got pregnant and stigmatization due to their sero- status, as illustrated in these comments “*Mmm... my parents cannot let me...you will be disappointed.... I do not even have a boyfriend, what I do when I reach home... I read school material and sleep.*” (Participant # 10).

### **Conclusion**

This chapter has presented findings of the study on ‘exploring the reproductive health needs and sexual practices of female adolescents with perinatally HIV’. The findings of these in-depth interviews indicated that HIV-positive adolescents have reproductive health needs; they lacked access to reproductive information and education of various types of contraceptives. They desire to be married and have children though they preferred to have them in future, even though they are engaging in risky sexual activities. However,

some felt that stigma and discriminations attached to their sero-status hinders them to have such aspirations. The findings further indicate a fair knowledge on contraceptives. The mostly used contraceptive method was injectable even though they portrayed lack of knowledge regarding emergency contraception and dual protection method. The study found that in general, fear of consequences of unwanted pregnancy was the strongest motivation for protection. The respondent's feared dropping out of school, and rejection from parents.

## **CHAPTER: 5**

### **DISCUSSION**

#### **Introduction**

This chapter discusses the findings of the current study in line with the study objectives. The aim of the study was to explore reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV attending clinic at Baylor Paediatric College of medicine. Specifically, the study investigated: the reproductive needs, contraceptive knowledge, access and use and finally the sexual practices of female adolescents with perinatally acquired HIV. The findings that will be discussed are according to the following major themes that emerged from the findings: Access to information/education and service; desire for children; meaning and types of contraceptives; commonly used contraceptives; reason for non-usage of contraceptives; point of contraceptive collection; sexual behaviour and reasons for and not indulging in sexual activities.

#### **Reproductive needs**

##### **Access to information/Education**

This study revealed a widespread ignorance amongst adolescents with regards to other reproductive service options available and how to use them. Adolescents expressed the need to access comprehensive health information during each visit. This statement was evident through use of injectable form of contraception by the participants as the only

mode of contraception they were offered. The result agrees with the study by Bakeera-Kitaka et al. (2007) on sexual risk reduction needs of adolescents with HIV in a clinical setting in Uganda. The findings show a limit in information on how to adopt safer sexual behaviour; suggesting scale up in information on access to effective contraception – alongside HIV prevention education in the primary HIV care setting. On the contrary, Francis (2010), acknowledges that there has been an increase in open discussions around sex in recent years in the global village, even though an affirming and positive definition of sexual health that takes account of physical attraction, sexual pleasure, desire and passion is still missing. Francis (2010) concludes that positive sexual education which avoids blaming and shaming youth about their sexual experiences and feelings, and which views sexuality as both risky and enjoyable has more likelihood to meet the needs of youth. All things considered, inadequate access to reproductive health education and information continues to be a persistent problem. According to (Obaid, 2009) it is the poorest girls and women who have the least access to information and services.

It was evident that the participants also wished to receive education on different types of contraception especially emergency contraceptives and other reproductive guidelines, stating it's enshrined in their human rights. Consistent with Cooper et al. (2006), in a study in South Africa where contraceptive prevalence is quite high compared to many other African countries, qualitative studies conducted among HIV and PMTCT clinic attendees showed that youth living with HIV had little knowledge of emergency contraception or how to access it. These findings have unearthed challenges adolescents face regarding access to SRH services.

Various studies indicate that comprehensive sexuality education (CSE), which is based on a rights approach, indeed supports young people in developing healthier and more satisfying relationships; it enables them to feel more confident in making informed choices about their sexuality, and to recognize their rights as sexual beings (Jewkes, 2009). Indeed, several indicators of SRHR are positively related to the level of educational attainment, and CSE can play an important role in advancing gender equality and to make sure that young people have access to information on sexual and reproductive health rights (Loaiza & Wong, 2012). Evidence has shown that CSE plays an important role in improving young people's sexual health and well-being, as it delays initiation of sexual activity, decrease the number of sexual partners, increase contraceptive and condom use, and decrease STIs including HIV (Kirby, 2006). Moreover, sexuality education helps reduce unintended pregnancies, thereby reducing the health risks associated with unsafe abortions and the negative influence of adolescent pregnancies in the enjoyment of other rights, e.g. curbing drop-out rates or expulsion from school because of pregnancies (Kirby, 2006; Santelli et al., 2006). Limited access to information contributes to the engaging in high risk behaviours. As ART programmes expand, survival among children is increasing and so is the number of adolescents needing ART. Scale-up will then need programmes that specifically address the particular needs of adolescents. Adolescents are usually managed in Paediatric programmes; service providers, are not trained to work with adolescents, yet evidence from a number of treatment programmes now shows that adolescents have specific challenges in relation to access to reproductive health.

## **Access to services**

The current study has shown that adolescents wanted providers to take time to hear and address their complex issues, and provide them with an opportunity to access the services of their preference. Adolescents pointed out negative attitudes from providers' towards provision of reproductive healthcare, mostly they felt uneasy and discouraged to talk more about sexuality due to the facial expressions they are met with, from the time they enter the service rooms. This is in line with Mwalabu (2014) who found that adolescents were challenged by the judgmental attitudes of service providers. Likewise, Werenius et al. (2006) examined the attitudes of nurses and midwives towards the SRH needs of adolescents in Zambia and Kenya. According to their findings, 81% of Zambian respondents opted to recommend abstinence. No wonder in the findings of this study suggest that the unique needs of adolescents living with HIV are more likely to remain unmet where such modes of service delivery are applied, the negative attitudes coming from the service providers is a reason adolescents opt to seek SRH from private providers for instance Banja la Mtsogolo. A useful correction measure in such instances would be to intensify professionalism in how to handle and serve HIV positive adolescents so that their concerns are addressed explicitly. Health care providers need to create an atmosphere in which adolescents could be heard as individuals, express their individual concerns, expectations, limitations, and be able to participate in the decision making concerning the reproductive health. Otherwise this experience could lead adolescents to seek information on issues related to sexuality from both informal and formal sources, including family, peers, school programmes, media (particularly radio) and pornography (Rijssdijk et al., 2013), these sources might have different importance and roles, providing different, sometimes contradictory types of information. These results obtained suggest that

adolescents have particular issues and vulnerabilities as such SRH information and services should enable young women to make informed decisions regarding their sexual practices, thus promoting optimal SRH outcomes (Birungi et al., 2008). As with all adolescents, adolescents living with HIV must be informed of their sexual and reproductive rights and must have access to medically sound counseling and services to facilitate informed reproductive health decision-making

### **Desire for children**

The current study has shown that participants value fertility, and indicated that they would want to have children although they were HIV positive. Participants expressed a strong desire to have children in the future. Similarly, Cooper., et al. (2009) in a study conducted in South Africa found that 29% of PLWHA wanted to have children in future. Likewise, Kakaire, Osinde and Kaye (2010) in Uganda, corroborates with this finding where 35% and 29% of PLWHA reported that they wanted to have more children in two separate studies respectively (Heys et al., 2009). Elsewhere in the world the fertility desires among HIV positives; 34% in Papua New Guinea, 28-9% in the USA and ranges between 15-55% in Eastern Africa (Berhan & Berhan, 2013). All these studies show that HIV positive's desire for fertility is wide spread.

Nevertheless, in Malawi there were no studies quoting the fertility desires in female HIV positive adolescents and so this was a first of its own, though seemingly a small study population for generalization, but, it represents an important population for healthcare providers. The findings indicate a more likely determinant of fertility desire was due to the fact that these adolescents had no children at the time of study, contrary to Mwalabu (2014), whose study found that most of the young women in the study had already fallen

pregnant. However, this may be due to the need to be a parent an HIV diagnosis notwithstanding.

This finding was similar to a meta-analysis of twenty studies from different parts of the world demonstrating that age less than 30 and having no child was a strong association to fertility desires (Berhan & Berhan, 2013). Results of this study have indicated that living with HIV does not hamper adolescent's future aspirates to found families and having biological children. Therefore, there is need to have access to information and services on family planning and safe reproduction health practices in order to make right decisions, understanding the health intentions is paramount.

Different views were evident from the study participants who did not want even to hear about children. This was a striking finding as it indicates negative responses with regards pregnancy desire. These participants acknowledge that HIV was primarily a sexually transmitted infection and it was acquired perinatally hence evoking feelings of bitterness and blame. Likewise, a study in Nigeria reported a significant negative association between HIV and fertility desires (Oladapo et al., 2005). Despite the contrary finding in other studies elsewhere, it can be suggested that the current study has shown that being infected with HIV does not negate desires for children as there is a strong indication of desire for children, despite the adolescents' HIV status. Therefore it can be concluded that there is growing evidence that increase in access to ART is changing the context of future childbearing for adolescents living with HIV/AIDS, prevailing values mean that, for many youths living with HIV/AIDS and having children is seen as necessary for a "normal" and healthy adult life (Wekesa & Coast, 2014), hence the need for healthcare providers working at ART sites to be alert to this and must discuss contraceptive options,

as well as readiness to discuss issues of having children, with adolescents of childbearing age on a regular basis.

### **Knowledge of contraceptives**

Participants discussed the meaning of contraception and explained its importance. Findings reveal an overwhelming understanding of contraceptive methods among adolescents. Participants were able to describe contraceptive as devices to prevent unwanted pregnancy and to prevent STDs; Most of them knew the types of contraceptives. Overall respondents knew of at least three contraceptive methods; others were able to explain at least one method. The mostly known type of contraception was injectable and condoms. Likewise, Birungi et al. (2008), a study on sexual and reproductive health needs of adolescents perinatally infected with HIV, findings revealed increase in contraceptive knowledge. A slight difference with this study was the Ugandan study Birungi et al. (2008) found that 84% of the study female respondents knew of at least one contraceptive method but, the condom was the most known method, followed by the contraceptive pill. However, our study suggests that knowledge did not translate into use, as the commonly used form of contraception was injectable mainly to prevent pregnancies in anticipation of struggles with condom use with their partners, leaving themselves vulnerable to HIV re-infection and contracting STIs.

### **Contraceptive use**

Participants reported using only one type of a method, commonly ever used are injectable form of contraception, similar with a study in Kenya where findings show a (22%) use of injectable and (7%) pills (Undie et al., 2009). This study has shown that

injectable form of contraception was regarded as the most appropriate method for HIV-positive individuals, because of the secrecy that surrounds the method. Participants in this study did not want others to know that they were on any contraception, hence preference for injectable contraceptives to prevent pregnancies in anticipation of struggles with condom use with their partners. These results are in agreement with those found in Kenya (Undie et al. 2009) and other African countries (Nobrega 2007; Mujugira et al., 2013; Laher et al., 2009; Agadjanian, 2005). These results obtained suggest that adolescents seem to prefer injectable form of contraception. Contrary to the findings of this study, was the study done in Kwazulu Natal (Somera, Crookes & Ross 2012). Somera, Crookes and Ross reported that 97% of participants were knowledgeable about injectable contraception, while only 40% used the latter as a form of contraception. Therefore, the use of only one type of contraception poses a widespread risky sexual behaviour. Strategies need to be put in place that increases the uptake and use of dual contraception. This may include but not limited to educating adolescents on the availability of such service.

Results reported in this study also supports previous research described from a study conducted in Malawi (Center for Social Research, 2004) which suggests that availability and knowledge pertaining to family planning methods alone does not define use of these services, hence there are other factors that influence choices on whether or not to accept and use such type of family planning methods, this however needs further exploration.

On the contrary some respondents stated that they were unclear what other methods other than injectable and condoms could be offered to them at the facility, this may suggest lack of provider initiated programs, as such SRH issues are not given due attention, which

often leaves sexually active HIV-positive adolescents unable to negotiate contraceptive use or even to access contraceptive methods (Baylor College of Medicine – Malawi, 2012).

Birungi et al. (2009) notes that increased availability of antiretroviral treatment and emphasis on treatment care and prevention, maternal and child health outcomes should improve for HIV-positives, including adolescents. However, emerging evidence indicates that the existing HIV/AIDS treatment, care and support programs in the region do not ask their adolescent clients about their SRH needs because most service providers advise these clients to refrain from or postpone sexual intercourse (Birungi et al., 2009).

Only one respondent said that she was discouraged on the use of oral contraceptive because of perceived contraindications for HIV-positives taking antiretroviral therapy (ART). However, she was not sure of the nature of the contra-indication. According to (Harries et al. 2007) providers' misconceptions regarding the safety of hormonal contraceptive methods among youths on ART may also play a role in limiting HIV-infected to access family planning (Hayford, 2010). Additionally, (Bakeera-Kitaka et al., 2007), explains how young people's sexual desires need to be taken seriously and discussed openly and acceptingly; otherwise, adolescents may not receive necessary information and skills for adopting safer sexual behaviours.

It can be concluded that, providing safe, effective contraception to HIV-infected youths who desire it has also been identified by the World Health Organization as a primary strategy for prevention of pediatric infections (WHO, 2012). The Malawi government's current recommendations (Ministry of Health, 2011) are that HIV-positives engaging in sexual activities should always use dual protection in order to prevent unplanned pregnancy and are encouraged to use condoms to prevent the likelihood of

acquiring another drug resistant strain of HIV or an STI, as well as utilize a reliable form of contraception (Johnson, 2012).

### **Dual protection**

Participants in this study reported using only one type of contraceptive. Similarly, in Ethiopia dual method of contraception was practiced by only 13.5% of the respondents (Lulu et al., 2014). Contrary findings are reported by another study conducted in India (Chakrapani, 2011) where condoms were the most common contraceptive method, with the prevalence of 92% using dual methods. Dual methods of contraception are preferred because they protect against horizontal spread of HIV and other STIs. The lower prevalence of condom use in the current study could be explained by limited acceptability of condom as contraceptives among HIV positives (Family Health International, 2010). The finding of low use of dual methods of contraception is consistent with the outcomes of a study conducted in Soweto, which showed that the importance of using condoms in preventing STIs and re-infection with HIV, as well as the need to use effective forms of contraception, was not clearly discussed with HIV-positive patients (Schwartz et al., 2012). Therefore, the use of injectable form of contraception minimizes the risk of unintended pregnancies but leaves youth still at risk of re-infections with HIV and contracting other STIs.

Equally, through a series of FGD's, (Chacko et al., 2007), also found a gap in knowledge about the use of dual methods to prevent both STI's, including HIV, and pregnancy. The authors suggest that this disconnect is related to a fragmentation in the delivery of health education about STI prevention and family planning (Chacko et al., 2007). The current study has shown unmet need for dual contraceptive, which remains high

amongst childbearing age groups of HIV-infected adolescents. Similarly, a cross section study on high pregnancy intentions and missed opportunities for patient provider communication about fertility in a South African cohort of HIV-positive women on antiretroviral therapy showed that the importance of using condoms in preventing STIs and re-infection with HIV, as well as the need to use effective forms of contraception, was not clearly discussed with HIV-positive patients (Schwartz et al., 2012). However, use of dual contraception methods and assessment of information given to adolescents with HIV needs further research. Baylor (2012) alludes to the fact that teens have difficulty accessing SRH services due to lack of truly adolescent friendly staff, stigma, unwelcoming clinical situations, lack of provider initiated family planning services and modesty or embarrassment. It is important that healthcare workers' guidance to patients whenever they visit the ART site is paramount, and to address any deficits in contraceptive knowledge and patients' willingness to use dual contraception methods (Stephenson, Grabbe & Vwalika 2010).

Studies have shown that with proper education dual contraception in HIV positives improve. For instance, in Zambia 59.2% of the youths who reported using current modern contraceptive after education 61.6% of them successfully accessed dual contraceptive services within 90 days (Chibwesha et al., 2011). Similarly, a study that was carried out in SA at two ART sites showed improvement in use of dual contraception from a baseline of 10% to 30%-35% (Cooper, 2007). Therefore, additional efforts are needed to promote reproductive health, particularly dual method use because of the substantial risk of unintended pregnancy and sexually transmitted infections (STIs) amongst HIV-infected,

linkages between HIV and reproductive health services are advocated (Marmot et al., 2008).

## **Sexual practices**

### **Condom use**

According to the findings participants rarely use condoms, unearthing risky sexual practices of not protecting themselves from STIs. Similarly, Johnson (2012) indicates that adolescents in Southern Africa have a less than 25% chance of negotiating condom use when engaging in sexual activities predisposing them to unwanted pregnancies, re-infecting themselves with a different strain of virus and contracting STIs. Participants explained that at times their partners resisted condom use as such they fail to negotiate condom use for fear of losing their boyfriend to other girls. Similar with findings of this study anecdotal evidence from The Aids Support Organization (TASO) in Uganda and from South Africa suggests that most HIV-positive adolescents are likely to seek sexual relationships, and have unprotected sex, with other HIV-positive young adults for fear of losing them to other girls (Birungi et al., 2008b).

According to (Turmen, 2003) in a prior study; condom use is the best protection against heterosexual transmission of HIV and other STIs, however, studies have identified that globally many youths find it difficult to negotiate for safe sex. Participants in this study desired injectable contraceptives to prevent pregnancies in anticipation of struggles with condom use with their partners. On the other hand, this study has uncovered that trust was also identified as one of the major factors for agreeing not to use condoms with their partners. Similarly, a study in Zambia showed that adolescents in long-term relationships

were likely to agree to none-use of condom than those in short-term ones (Chibwesha et al., 2011).

In agreement with the current study generally condom use among young people in Malawi remains relatively low (Government of Malawi, 2010). Despite extensive efforts in promoting condom use, 98% of young people aged 15-19 have ever heard about a modern method of contraceptives and 20% have ever used the methods including condoms, yet 50% are sexually active and not married (Government of Malawi, 2010). The current study has revealed low use of condoms amongst adolescents with perinatally acquired HIV posing a challenge between having knowledge and the actual practice of condom use. However, the available data on condom use in adolescents in Malawi is limited it mostly relies on quantitative (survey) methodologies, and takes on a so-called knowledge-attitudes practices format which tends to be descriptive (Government of Malawi, 2010). In this context condoms are often considered as a supplementary contraceptive method not an obvious focus (Mwalabu, 2014), making it difficult to differentiate factors linked specifically to condom use or identify the underlying forces behind such sexual practices.

### **Sexual behaviour**

#### ***Sexual debut***

Findings revealed that participants experienced sexual intercourse as early as 15 years old. The findings agree with the 2010 Malawi Demographic and Health Survey, 14% of youths aged 15 to 24 years initiated sexual activity before the age of 15 years. This finding substantiates prior findings globally (excluding China), where 11 per cent of adolescent girls are sexually active before age 15 (WHO 2008). A study that was carried

out in Canada demonstrated that young people start having unprotected sexual relationships at an average age of 14 for girls and 15 for boys (Fernet et al., 2011). Therefore, these results imply the need to intensify efforts to inform and educate adolescents about responsible and healthy attitudes towards sexuality and the need to decrease risky sexual practices. The adolescents and young children should be targeted with the appropriate information when they are still fairly young (Mwalabu, 2014).

### **Unprotected sex**

It is of concern that despite the high knowledge the adolescents portrayed with regards condoms and other methods of family planning, the respondents reported having had sexual intercourse, some of the participants admitted to having unprotected sex in the last six months. Similarly, studies have documented that the majority of young people who are sexually active often do not adopt protective measures (Obare & Van der Kwaak, 2010; Birungi et al., 2009; Bell et al., 2007). In the United States, findings of the study showed close to 2/3 of adolescents who participated in the study to be sexually experienced and approximately half of them had engaged in unprotected sexual practices since becoming aware of the diagnosis (Koenig et al., 2009). The author concludes that the risky sexual behaviour of perinatally infected adolescents is greater than previously estimated and points to the need of appropriate educational tools for early guidance in sexuality and health of these young people (Koenig et al., 2009).

A significant finding in the current study is that participants had consensual first sex. The study suggests a feeling of trust and being safe with their partner. Similar findings are in a study conducted in Kenya, Guiella and Madise (2009) where reason for non-use of condoms is that both sexually-active female and male adolescents reported that they felt

safe with their partner. Therefore, adolescents should be given information about and access to contraceptive and STI services before they begin to have sex, so that they are more likely to use protection when they do have sex

### **None indulgence in sexual activities**

A major finding of this study indicate that some of the participants had no desire to engage in sexual activities reason being that, their condition does not dictate so, however, they wished to have children in future. The respondent's feared stigmatization due to their sero- status if they indulged in sexual activities. The findings suggest a feeling of guilt and blame. Likewise, a study by (Berhane et al., 2006), reveals that HIV infection may affect sexuality because of fear of infecting the sexual partner(s), feelings of guilt and shame aggravated by stigma related to HIV, or emotional or psychological distress, reducing desire for or interest in sexual relations. The finding is consistent with (Tylee et al., 2007) who reported stigma among adolescent females living with HIV as a key barrier. Stigma of premarital sex, perpetuated by parents, providers and other community members has been shown to be the primary barrier in HIV-infected adolescents in seeking reproductive health services in resource-limited countries their study concluded. This study has gone further to indicate that the fear of stigma related to engaging in premarital sex is coming from a variety of different individuals in these adolescents' social network. This further compounds the stigma these adolescents already face due to their HIV-positive status and the possibility that their HIV infection was obtained through sexual transmission (Idele et al., 2014). Therefore, it is important that, HIV programmes recognize the relationships between adolescent females living with HIV and their parents, partners, health providers and communities are crucial in enhancing adolescents' use of contraception.

## **Conclusion**

The study looked at reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV. The study has unearthed challenges adolescents face with regard reproductive services as they expressed ignorance on other reproductive options available and how to use them, they wished to access comprehensive health information during each visit. They also wished to receive education on different types of contraception and other reproductive guidelines. The study revealed that the desire to have children in future was common amongst participants. Knowledge of contraception was high. However, there seemed to be a huge gap between their knowledge of different types of contraception and access to these services. The study demonstrated that the commonly used contraceptive was injectable form, due to the secrecy surrounding it. It was noted that participants were not using dual protection methods of contraception even though results indicate adolescents being sexually active and are engaging in risky sexual encounters as they engage in unprotected sex. This calls for concerted effort to offer comprehensive reproductive health services which are tailored at the adolescents needs, actively involving them in decision with regards their health.

## **Study limitations**

Perhaps the strongest limitation to qualitative research is that the quality of the research depends too greatly on the individual researcher. Because the researcher designs the type of questions she will ask, she can inadvertently influence the results due to her own personal beliefs. Furthermore, in purposive sampling there is no equal chance for others to participate in the study, as the researcher implies judgment in the selection of the participants (Brink, 2010), in addition with purposively sampling, the findings cannot be

generalized to a wider population. The methodology and size of the sample of this study place limitations on the generalizability of the findings to adolescents living with HIV, but nevertheless, it provides a revealing account of adolescent's reproductive needs, dating, marriage, contraceptive knowledge access and use, and sexual experiences in the context of a life with HIV.

As female adolescents were sampled from an urban clinic in one city, it cannot be said to what extent these findings represent experiences of female adolescents in other regions of the country, particularly rural areas. However, the purpose of these interviews was not to produce generalized findings, but rather to describe in depth the experiences of female adolescent born with HIV in this setting.

HIV and AIDS is a sensitive area since it deals with sexual issues which are considered private, hence the envisaged difficulty in collecting information with regards knowledge of contraception and HIV transmission, and if they report STI symptom and sexual behaviour (age of sexual debut, use of condom, multiple sex partners and enquiry in to reason for sexual debut). As envisaged some participants felt uncomfortable to discuss private issues through a tape recorder, especially that the participants were adolescents, this is a time when they portray insecurity, hence the tape recorder not being used in the majority of interviews. However, they were assured of confidentiality and anonymity during and after interviews.

### **Recommendations**

- Strategies need to be put in place to inform adolescents on availability of different types of reproductive health services.

- Routinely making enquiries about contraceptive usage and adolescents desire to have a child.
- Need to intensify integration of HIV and family planning services to improve dual contraception use and emergency contraceptives
- Tailored interventions are required for adolescents living with HIV to improve their sexual and reproductive health

### **Areas for further study**

The current study focused on reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV. However, the findings suggest further research required on the following key area: (i) Barriers to access dual contraception and use. (ii) Integration of HIV care, SRH and antenatal services. (iii) HIV positive adolescent-provider relationship (iv) quality of information/education given to adolescents (v) factors that facilitate or hinder use of contraceptives. (vi) involvement of males in the reproductive health choices.

## References

- Bakeera-Kitaka, S., Nabukeera-Barungi, N., Nöstlinger, C., Addy, K., & Colebunders, R. (2008). Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS Care, 20* (4), 426-433.
- Battles, H. B., & Weiner, L. S. (2002). From adolescence through young adulthood: Psychosocial adjustment associated with long term survival of HIV. *Journal Adolescent Health, 30*(3), 161-181.
- Bauermeister, J. A., Elkington, K., Brackis-Cott, E., Dolezal, C., & Mellins, C. A. (2009). Sexual behavior and perceived peer norms: Comparing perinatally HIV-infected and HIV-affected youth. *Journal of Youth and Adolescence, 38*(8), 1110-1122.
- Beyeza-Kashesya, J., Kaharuza, F., Ekström, A. M., Neema, S., Kulane, A., & Mirembe, F. (2011). To use or not to use a condom: a prospective cohort study comparing contraceptive practices among HIV-infected and HIV-negative youth in Uganda. *BMC Infectious Diseases, 11*(1), 144.
- Baylor International Pediatric AIDS Initiative. (2012). *Malawi teen club curriculum part 1: content. A resource for groups working with adolescents living with HIV.* Accessed on 13-06-2013, from [http://www.bipai.org/uploadedFiles/Educational\\_Resources/Part\\_1\\_Teen\\_Club\\_Content\\_2012\\_final\[1\].pdf](http://www.bipai.org/uploadedFiles/Educational_Resources/Part_1_Teen_Club_Content_2012_final[1].pdf).
- Baryamutuma, R., & Baingana, F. (2011). Sexual, reproductive health needs and rights of young people with perinatally Acquired HIV in Uganda. *African Health Science, 11*(2), 211–218.

Birungi, H., Obare, F., Mugisha, J. F., Evelia, H., & Nyombi, J. (2009). Preventive service needs of young people perinatally infected with HIV in Uganda. *AIDS Care*, 21(6), 725–731.

Birungi, H., Mugisha, J. F., Obare, F. & Nyombi. J.K. (2009). Sexual behaviour and desires among adolescents perinatally infected with human immunodeficiency virus in Uganda: implications for programming. *Journal of Adolescent Health*, 44(2), 184-187.

Birungi, H., Mugisha, J. F., Nyombi, J., Obare, F., Evelia, H., & Nyinkavu, H. (2008). *Sexual and reproductive health needs of adolescents perinatally infected with HIV in Uganda*. Frontiers Final Report. Washington, DC: Population Council.

Burns, N. & Grove, S. K. (2009). *The Practice of nursing research: Appraisal, synthesis and generation of evidence*. (6<sup>th</sup> Ed.). St Louis, Missouri: Saunders Elsevier.

Brink, H. (2010). *Fundamentals of research methodology for health care professionals*. Cape Town: Juta.

Campbell M., Hodoglugil N. & Potts M. (2006). Barriers to fertility regulation: A review of the Literature, *Studies in Family Planning*, 32: 87-98

Center for Social Research, Save the Children Federation USA, Malawi Ministry of Health and Population, MEASURE Evaluation.2004. Avoiding unwanted pregnancy and sexually transmitted infections: A rural Malawi district study. Chapel Hill, NC: MEASURE Evaluation.

Chibwesha, C.J., Li, M.S., Matoba, C.K., Mbewe, R.K., Chi BH., Stringer, J.S., and Stringer, E. M. (2011). Modern contraceptive and dual method use in HIV-infected women in Lusaka, Zambia. *Infectious Diseases in Obstetrics and*

*Gynecology Volume 2011 (2011), Article ID 261453, 8 pages*

<http://dx.doi.org/10.1155/2011/261453>

- Cooper, D., Moodley, J., Zweigenthal, V., Bekker, L. G., Shah, I., & Myer, L. (2009). Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: implications for integrating reproductive health and HIV care services. *AIDS and Behavior*, 13(1), 38-46.
- Cooper, D., Bracken, H., Myer, L., Zweigenthal, V., & Harries, J. (2005). *Reproductive intentions and choices among HIV- infected individuals in Cape Town, South Africa: Lessons for reproductive policy and service provision from a qualitative study*. Cape Town: University of Cape Town and Population Council.
- Chibber, R., & Khurranna, A. (2005). Birth outcomes in perinatally HIV-infected adolescents and young adults in Manipur, India: a new frontier. *Archives of Gynecology and Obstetrics*, 271(2), 127-131.
- Craft, S. M., Delaney, R. O. & Bautista, D. T. (2007). Pregnancy decisions among women with HIV. *AIDS Behavior*, 11 (6), 927-935.
- Das S., Mukherjee, A., Lodha, R., and Vatsa, M. (2010). Quality of life and psychosocial functioning of HIV infected children. *The Indian Journal of Paediatrics*. 77(6), 633-637.
- Delvaux, T. & Nostlinger, C. (2007). Reproductive Choice for Women and Men Living with HIV: Contraception, Abortion and Fertility. *Reproductive Health Matters*, 15(29), 46–66.
- Ezeanolue, E. E., Wodi, A. P., Patel, R., Dieudonne, A., & Oleske, J. M. (2006): Sexual behaviours and procreational intentions of adolescents and young adults with

- perinatally acquired human immunodeficiency virus infection: Experience of an urban tertiary center. *Journal of Adolescent Health*, 38(6), 719-725.
- Fatusi, A. O., & Hindin, M. J. (2010). Adolescents and youth in developing countries: Health and development issues in context. *Journal of Adolescence*, 33(4), 499-508.
- Fasawe, O., Avila, C., Shaffer, N., Schouten, E., Chimbwandira, F., Hoos, D., ... & De Lay, P. (2013). Cost-effectiveness analysis of option B+ for HIV prevention and treatment of mothers and children in Malawi. *PLoS One*, 8(3), e57778.
- Fernet, M., Wong, K., Richard, M. E., Otis, J., Lévy, J. J., Lapointe, N., ... & Trottier, G. (2011). Romantic relationships and sexual activities of the first generation of youth living with HIV since birth. *AIDS care*, 23(4), 393-400.
- Felton, G. M & Bartoces, M. (2009). Predictors of initiation of early sex in black and white adolescent females. *Public Health Nursing*, 19(1), 59-67.
- Fielden, S.J., Sheckter, L., Chapman, G.E., Alimenti, A., Forbes, J.C., Sheps, S., Frankish, J.C. (2006). Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care*, 18 (8), 1050-1053.
- Francis, D.A. (2010). Sexuality education in South Africa: Three essential questions. *International Journal of Educational Development*, 30, 314-319.
- Global Youth Coalition on HIV/AIDS. (2007). *Youth and HIV fact sheet*. Accessed on 4<sup>th</sup> – 11-2013 from <http://www.youthaidscoalition.org/page/ypdata>.

- Gortmaker, S. L., Hughes, M., Cervia, J., Brady, M., Johnson, G. M., Seage III, G. R., ... & Oleske, J. M. (2001). Effect of combination therapy including protease inhibitors on mortality among children and adolescents infected with HIV-1. *New England Journal of Medicine*, 345(21), 1522-1528.
- Gruskin, S., Ferguson, L. & O'Malley, J. (2007). Ensuring sexual and reproductive health for people living with HIV: an overview of key human rights, policy and health systems issues. *Reproductive Health Matters*, 15(29), 4–26.
- Hayford, S. R & Agadjanian V. (2010). Providers' views concerning family planning service delivery to HIV-positive women in Mozambique. *Studies in Family Planning*. 41(4), 291–300.
- Harrington, E. K., Newmann, S. J., Onono, M., Schwartz K.D., Bukusi, E.A., Cohen C. R., & Grossman, D. (2012). Fertility intentions and interest in integrated family planning services among women living with HIV in Nyanza Province, Kenya: A qualitative study. *Infectious Diseases in Obstetrics and Gynecology*. Article ID 809682, doi:10.1155/2012/809682.
- Harries, J., Cooper, D., Myer, L., Bracken, H., Zweigenthal,,V. & Orner, P. (2007) Policy maker and health care provider perspectives on reproductive decision making amongst HIV infected individuals in South Africa. *Biomed Central Public Health*, 7(1), 282.
- Heys J., Kipp W., Jhangri G., Alibhai A., & Rubaale T. (2009). Fertility desires and infection with the HIV: results from a survey in rural Uganda. *AIDS*, 23: S37–45.
- Hodgson, I., Ross, J., Haamujompa, C., & Gitau-Mburu, D. (2012). Living as an adolescent with HIV in Zambia—lived experiences, sexual health and reproductive needs. *AIDS care*, 24(10), 1204-1210.

- Hoffman, I. F., Martinson, F. E., Powers, K. A., Chilongozi, D. A., Msiska, E. D., Kachipapa, E. I., ... & Tsui, A. O. (2008). The year-long effect of HIV-positive test results on pregnancy intentions, contraceptive use, and pregnancy incidence among Malawian women. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 47(4), 477-483..
- Homsy, J., Bunnell, R., Moore, D., King, R., Malamba, S., Nakityo, R., ... & Mermin, J. (2009). Reproductive intentions and outcomes among women on antiretroviral therapy in rural Uganda: a prospective cohort study. *PloS one*, 4(1), e4149.
- International HIV/AIDS Alliance. (2011). *How national AIDS responses are failing in prevention efforts for key populations – an analysis of available data*. Accessed on 17<sup>th</sup>-05-2013 from <http://www.whatspreventingprevention.org/wp-content/uploads/2011/06/UNreportskeypopulations.pdf>.
- Jewkes, R. (2009). *Growing up sexual in the age of HIV & AIDS*. In: C. Mitchell & K. Pithouse, (Eds.). Teaching and HIV& AIDS in the South African Classroom. Northlands: Macmillan, pp. 147–158.
- Johnsoän L. F. (2012). Access to antiretroviral treatment in South Africa, 2004-2011. *South African Journal of HIV Medicine*. 3, 22-27.
- Kakaire O, Osinde M. & Kaye D. (2010). Factors that predict fertility desires for people living with HIV infection at a support and treatment centre in Kabale, Uganda. *Reproductive Health*, 7 (1), 2-7.
- Kenny, J., Williams, B., Prime, K., Tookey, P and C. Foster, C. (2012). Pregnancy outcomes in adolescents in the UK and Ireland growing up with HIV. *HIV Medicine*, 13 (5), 304–308,

- Koenig, L. J., Espinoza, L., Hodge, K., & Ruffo, N. (2007). Young, seropositive, and pregnant: Epidemiologic and psychosocial perspectives on pregnant adolescents with human immunodeficiency virus infection. *American Journal of Obstetrics and Gynecology*, 197(3), S123–S131.
- Koenig L., Pals J., Sherri Chandwani L., Sulachni H., Abramowitz K., Barnes S. & D'Angelo W. (2010). Sexual transmission risk behavior of adolescents with HIV acquired perinatally or through risky behaviors. *Journal of Acquired Immune Deficiency Syndromes*, 55(3), 380-390.
- Kirby, D. (2002). Antecedents of adolescent initiation of sex, contraceptive use, and pregnancy. *American Journal of Health Behaviour*, 26 (6), 473 – 85.
- Kirby, D. B., Laris, B. A., & Rolleri, L. A. (2007). Sex and HIV education programs: their impact on sexual behaviors of young people throughout the world. *Journal of Adolescent Health*, 40(3), 206-217.
- Laher F., Todd C.S., Stibich M. A., Phofa R., Behane X., Mohapi L. & Gray G: (2009). A qualitative assessment of decisions affecting contraceptive utilization and fertility intentions among HIV-positive women in Soweto, South Africa. *AIDS and Behavior*, 13(1), 47-54.
- Lavender T., Edwards, G. & Alfirevic, Z. (2004). *Demystifying qualitative research in pregnancy and childbirth*. London: MA Healthcare Limited.
- Li, R. J., Jaspan, H. B., O'Brien, V., Rabie, H., Cotton, M. F., & Nattrass, N. (2010). Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care*, 22(6), 751-758.
- Loaiza Sr, E., & Wong, S. (2012). *Marrying too young. End child marriage*. New York, New York: United Nations Population Fund

- London, L., Orner, P. J. & Myer, L. (2008). Even if you're positive you still have rights because you are a person.' Human rights and reproductive choice of HIV-positive persons. *Developing World Bioethics*, 8 (1), 11–22.
- MANET+. (2003). *Voices for equality and dignity: Qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi*. Accessed on 17<sup>th</sup>-05-2013 from www.policyproject.com/pubs/countryreports/MALA\_MANET\_FGD.
- Malawi Demographic Health Survey, (2004). *Social Data*. Lilongwe: Malawi Government. (2010). *Malawi HIV and AIDS monitoring and evaluation report 2008-2009. UNGASS Country Progress Report*. Lilongwe: National AIDS Commission
- Malawi Government. (2011). *Health Sector Strategic Plan*. Lilongwe: Ministry of Health.
- Malawi National HIV and AIDS Strategic Plan. (2011 – 2016). *National HIV and AIDS Response*. Lilongwe: National AIDS Commission.
- Malawi Government National HIV and AIDS. (2010–2012). *Action Framework*. National AIDS Commission, Lilongwe, Malawi.
- Marmot, M., Friel, S., Bell, R., Houweling, T. A., Taylor, S., & Commission on Social Determinants of Health. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. *The Lancet*, 372(9650), 1661-1669.
- Meekers D. & Richter K. (2005). Factors associated with the use of female condom usage in Zimbabwe. *International Family Planning Perspectives* 31, (1), 30-37.
- Myer, L., Carter, R. J., Katyal, M., Toro, P., El-Sadr, W. M., & Abrams, E. J. (2010). Impact of antiretroviral therapy on incidence of pregnancy among HIV-infected women in Sub-Saharan Africa: a cohort study. *PLoS Med*, 7(2), e1000229.

- Mialky, E., Vagnoni, J., & Rutstein, R. (2001). School-age children with perinatally acquired HIV infection: Medical and psychosocial issues in a Philadelphia cohort. *AIDS Patient Care and STDs*, 15(11), 575-579.
- Millery, M., Vazquez, S., Walther, V., Humphrey, N., Schlecht, J. & Devanter, N. V. (2012). Pregnancies in Perinatally HIV-Infected young women and implications for care and service programs. *Journal of the Association of Nurses in AIDS Care*, 23(1), 41-51.
- Ministry of Health (2009). *National Sexual and Reproductive Health and Rights (SRHR) Policy*. Lilongwe, Malawi Ministry of Health.
- Ministry of Health (2011). *Malawi Guidelines for Clinical Management of HIV in Children and Adults*. Accessed on 15<sup>th</sup>-04-2013 from [www.hivunitmohmw.org](http://www.hivunitmohmw.org)
- Mugoni P. (2011) *Exchange on HIV and AIDS, sexuality and gender: Adolescent sexuality for young people living with HIV*. Accessed on 16<sup>th</sup>-05-2013 from [www.safaids.net](http://www.safaids.net).
- Munthali, A., Moore, A. M., Konyani, S. & Zakeyo, B. (2006). *Qualitative evidence of adolescents' sexual and reproductive health experiences in selected districts of Malawi*. (Occasion Report No. 23). New York: Allan Guttmacher Institute.
- Mwalabu, G. G. T. (2014). *Telling their story: perspectives of young women, their caregivers and service providers regarding the experiences of growing up with perinatally-acquired HIV in Malawi* (Unpublished doctoral dissertation, University of Nottingham, Nottingham, UK).

Nalwadda, G., Mirembe, F., Byamugisha, J. & Faxelid, E. (2010). Persistent high fertility in Uganda; Young people recount obstacles and enabling factors to use of contraceptives. *BMC Public Health, 10(1)*, Accessed on 15<sup>th</sup>-04-2013 from <http://www.biomedcentral.com/1471-2488/10/530>.

National Statistical Office (NSO) and ICF Macro. (2011). *Malawi Demographic and Health Survey 2010*. Zomba, Malawi: and Calverton, Maryland, USA: NSO and ICF Macro.

Neema, S., Musisi, N., & Kibombo, R. (2004). *Adolescent sexual and reproductive health in Uganda: A synthesis of the research evidence*. Occasional Report No. 14. New York: The Alan Guttmacher Institute.

Nebié, Y., Meda, N., Leroy, V., Mandelbrot, L., Yaro, S., Sombié, I., ... & Nacro, B. (2001). Sexual and reproductive life of women informed of their HIV seropositivity: a prospective cohort study in Burkina Faso. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 28*(4), 367-372.

Obaid, T. A. (2009). Fifteen years after the International Conference on Population and Development: What have we achieved and how do we move forward? *International Journal of Gynecology & Obstetrics, 106*(2), 102-105.

Obare, and Birungi H. (2010). The limited effect of knowing they are HIV-positive on the sexual and reproductive experiences and intentions of infected adolescents in Uganda. *Population Studies, 64*(1), 97-104.

Obare, F., Birungi, H. & Kavuma, L. (2011). Barriers to sexual and reproductive health programming for adolescents living with HIV in Uganda. *Population Research and Policy Review, 30*(1), 151-163.

- Okereke C.I. (2010): Assessing the prevalence and determinants of adolescents' unintended pregnancy and induced abortion in Owerri, Nigeria. *Journal of Biosocial Science*, 42(05), 619-632.
- Orner, P., Cooper, D., Myer, L., Zweigenthal, V., Bekker, L. G., & Moodley, J. (2008). Clients' perspectives on HIV/AIDS care and treatment and reproductive health services in South Africa. *AIDS Care*, 20(10), 1217-1223..
- Peltzer, K., Chao, L. W., & Dana, P. (2009). Family planning among HIV positive and negative prevention of mother to child transmission (PMTCT) clients in a resource poor setting in South Africa. *AIDS and Behavior*, 13(5), 973-979.
- Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: Appraising evidence for nursing practice*. (7<sup>th</sup> Ed.). Philadelphia: Wolters Kluwer, Lippincott & William & Wilkins.
- Polit D. F., & Beck, C. (2006). *Essentials of nursing research; Methods, appraisal and utilization*. (6<sup>th</sup> Ed), Philadelphia: J.B. Lippincott Company.
- Rongkavilit, C., Naar-King S., Chuenyam T., Wang B., Wright K. & Phanuphak P. (2007). Health Risk Behaviours among HIV-Infected Youth in Bangkok, Thailand. *Journal of Adolescent Health*, 40, (4), 358.e1-358.e8.
- Reynolds, H. W., Janowitz, B., Wilcher, R., & Cates, W. (2008). Contraception to prevent HIV-positive births: current contribution and potential cost savings in PEPFAR countries. *Sexually Transmitted Infections*, 84 (2), 49–53.
- Rochat, T. J., Richter, L. M., Doll, H. A., Buthelezi, N. P., A. Tomkins, A. & Stein, A. (2006). Depression among pregnant rural South African women undergoing HIV testing. *Journal of the American Medical Association*, 295 (12), 1373–1378.

- Rice, E., Batterham, P., & Rotheram-Borus, M. J. (2006). Unprotected sex among youth living with HIV before and after the advent of highly active antiretroviral therapy. *Perspectives on Sexual and Reproductive Health, 38*(3), 162-167.
- Rijsdijk, L. E., Lie, R., Bos, A. E., Leerlooijer, J. N., & Kok, G. (2013). Sexual and reproductive health and rights: implications for comprehensive sex education among young people in Uganda. *Sex Education, 13*(4), 409-422.
- Santelli, J., Ott, M., Lyon, M., Rogers, J., summers, D., & Schleifer, R. (2006). Abstinence and abstinence-only education: A review of U.S. policies and programs. *Journal of Adolescent Health, 38*(1), 72-81.
- Shaw, D. (2009). Access to sexual and reproductive health for young people: Bridging the disconnect between rights and reality. *International Journal of Gynecology & Obstetrics, 106*(2), 132-136.
- Shire, A., Ahmed, S., & de Bruyn, M. (2006). *Sexual and reproductive health of HIV positive women and adolescent girls: a dialogue on rights policies and services. Global electronic forum*. Report on results. Harvard: Harvard University/ICP/IPAS/UNFPA
- Singh, S., Bankolea, A., & Wooga, V. (2006). Evaluating the need for sex education in developing countries: sexual behavior, knowledge of preventing sexually transmitted infections/HIV and unplanned pregnancy. *Sex Education: Sexuality, Society and Learning 5*(4), 307-331.
- Speizer, I. S., & White, J. S. (2008). The unintended consequences of unintended pregnancies: youth, condom use and HIV transmission in Mozambique. *AIDS Education and Prevention, 20*(6), 531-546.

- Stemler, S. (2001). An overview of content analysis. *Practical Assessment, Research & Evaluation*, 7(17), 137-146.
- Stover, J., Johnson, P., Hallett, T., Marston, M., R Becquet, R., & Timaeus, I. M. (2010). The Spectrum projection package: Improvements in estimating incidence by age and sex, mother-to-child transmission, HIV progression in children and double orphans. *Sexually Transmitted Infections*, 86(Suppl 2), ii16-ii21.
- Somera Y.S, Crookes G.J., & Ross A. (2013). Contraceptive knowledge and practice among HIV-positive women receiving antiretroviral therapy at a district hospital in KwaZulu-Natal. *South African Family Practice*, 55(2), 196-200.
- Schwartz, S. R., Mehta, S. H., Taha, T. E., Rees, H. V., Venter, F., & Black, V. (2012). High pregnancy intentions and missed opportunities for patient-provider communication about fertility in a South African cohort of HIV-positive women on antiretroviral therapy. *AIDS and Behavior*, 16(1), 69-78.
- Speizer I.S and White J.S (2008). The unintended consequences of unintended pregnancies: youth, condom use and HIV transmission in Mozambique. *AIDS Education and Prevention*, 20(6), 531-546.
- Stephenson, R., Grabbe, K., Vwalika, B., Ahmed, Y., Vwalika, C., Haworth, A., Fuller, L., Liu, F., Chomba, E., & Allen, S. (2010). The influence of informed consent content on study participants' contraceptive knowledge and concerns. *Studies in Family Planning*, 41 (3), 217-224.
- The Alan Guttmacher Institute (2005). *Adolescents in Malawi: Sexual and Reproductive Health*. Accessed on 30<sup>th</sup> 05-2013 from [www.guttmacher.org](http://www.guttmacher.org).
- Turmen, T. (2003). Gender and HIV/AIDS. *International Journal of Gynaecology and Obstetrics*, 82, 411-418.

Ulin, P.R., Robinson, E.T., Tolley, E.E., & McNeill, E.T. (2005). *Qualitative methods: a field guide for applied research in sexual and reproductive health*. San Francisco: Jossey-Bass Publishers.

UNAIDS. (2010) "UNAIDS Report on the Global AIDS Epidemic". Accessed on 20<sup>th</sup>-03-2013 from [http://www.unaids.org:80/globalreport/Global\\_report.htm](http://www.unaids.org:80/globalreport/Global_report.htm).

United Nations. (2013). *Commission on Human Rights Committee on the Rights of the Child, General Comment No. 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health*. (Art. 24), New York: UN.

United Nations. (2010). *Universal declaration of human rights. Dignity and justice for all of us*. New York: UN

UNFPA. ( 2005). *Youth and HIV/AIDS Fact Sheet*. Accessed on 12<sup>th</sup>-05-2013, from [www.unfpa.org/swp/2005/presskit/factsheets/facts\\_youth.htm](http://www.unfpa.org/swp/2005/presskit/factsheets/facts_youth.htm).

Warenius, L. U., Faxelid, E. A., Chishimba, P. N., Musandu, J. O., Ong'any, A. A., & Nissen, E. B. (2006). Nurse-midwives' attitudes towards adolescent sexual and reproductive health needs in Kenya and Zambia. *Reproductive Health Matters*, 14 (27), 119-128.

Wekesa E & Coast E. (2014). Fertility desires among men and women living with HIV/AIDS in Nairobi slums: A mixed methods study. *PLoS One* 9 (8), e106292. doi: 10.1371/journal.pone.0106292

World Health Organization (2010). *PMTCT Strategic Vision 2010–2012*. World Health Organization, Geneva, Switzerland.

- Wiener, L. S., Battles, H. B. & Wood, L. V. (2007). A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: Sexual knowledge, risk reduction self-efficacy and sexual behavior. *AIDS and Behaviour*, 11 (3), 471-478.
- Wood, K., & Jewkes R. (2006). Blood blockages and scolding nurses: Barriers to adolescent contraceptive use in South Africa. *Reproductive Health Matters*, 14(27):109–118.
- Zorrilla, C., Febo, I., Ortiz, I., Orengo, J. C., & Miranda, S. (2003). Pregnancy in perinatally HIV-infected adolescents and young adults--Puerto Rico 2002. *MMWR. Morbidity and Mortality Weekly Report*, 52(8), 149-151.

## **APPENDICES**

### **APPENDIX A: INFORMED CONSENT FORM**

#### **CLIENT INFORMATION SHEET**

##### **Introduction**

You are being invited to take part in a study on the reproductive health needs and sexual practices of adolescents with perinatally acquired HIV. Before you participate in the study, it is important for you to understand why the research is being done and what it will involve. Please feel free to ask if there is anything that is not clear or if you would like more information. Participation is voluntary.

##### **What is the purpose of the study?**

The aim of this study is to explore reproductive health needs and sexual practices of adolescents with perinatally acquired HIV. The findings from the study may be used to contribute to policy and program development that might assist in identifying the appropriate support systems for HIV positive youth. The findings may also assist in identifying ways to provide reproductive health services which are tailor made to suit the needs, thereby enhancing accessibility of these services depending on the identified reproductive health needs.

##### **Who will participate in the study?**

18-19 year olds are eligible to participate in this study. It is estimated that 15 female adolescents, who have declared their HIV status have the right to participate.

##### **Do I have to take part?**

You are free to take part or not in the study. You are also free to withdraw at any time you feel like without giving reasons. Your refusal to take part in the study will not affect the standard of care rendered in clinical care.

If I take part in the study, what will happen to me?

As a participant of this study, you will meet the investigator at a place where there will be audio-visual privacy. The investigator will use an audio tape to record your information if you grant permission. Detailed notes will also be taken where necessary. You are free to tell the investigator to turn off the recorder at any point during the conversation if you are not comfortable with the information you are giving. You are free not to answer any question you feel uncomfortable to answer. You will be asked to give information on your experiences with regards relationships and sexuality, factors that facilitate or hinder use of contraceptives and fertility needs. You will be asked to narrate your own experiences, giving explanations and descriptions where necessary. The interviews will last about 60 - 90 minutes. At any time during the interview you may decide to withdraw, you are free to do so. If you decide to withdraw no more information will be collected from you. When you indicate your wish to withdraw the investigator will ask if the material already collected so far could be used in the study. After the interview, the tape will be transcribed. You may see the transcript upon request and delete anything you do not want included or you may wish to add information. The information about you will be confidential and no one will identify who gave which information. Codes will be used instead. The tape recorder used to record information from you will not be used for any other purpose and will be kept under lock and key.

How will my privacy be ensured?

The researcher is required to maintain confidentiality regarding your identity. However findings of this study may be used for teaching, research, publications or presentations at scientific meetings. In case your individual findings are discussed your identity will be protected by using a code number rather than your name or other identifying information.

Is there any financial benefit for me if I take part in the study?

There is no payment for participating in this study. However, in the event that you have spent money on transport to the place of interview, the researcher will reimburse the transport money.

What are the possible benefits in taking part?

There are no direct benefits to you as an individual. The study findings however, will assist in service providers to lobby for increased recognition of special reproductive health needs of HIV positive adolescents, thereby creating and providing tailor made adolescent friendly HIV reproductive health care services.

What are the possible risks for taking part?

The probable risk include long period for the in-depth interview, and you may be uncomfortable with some of the questions and issues about personal situations. Some of your information may be embarrassing. You may skip any information that makes you uncomfortable, or withdraw from the study.

Contact for further information

If you need further information or you are worried about any aspect of the study, please contact Mrs. Beatrice Mkandawire (cell number 0999 918 029). Or you can call the Secretariat of COMREC on telephone number **01871911**.

**APPENDIX B: KALATA YOFOTOKOZERA OTENGA MBALI MU**  
**KAFUKUFUKU (CHICHEWA VERSION OF CLIENT INFORMATION SHEET)**

Mawu oyamba

Mulikupemphedwa kutenga mbali mukafukufuku wofufuza za “zilakolako za achinyamata amene ana badwa ndi HIV pa kani ya ubereki ndi kani ya kugonana”. Inuyo ngati mmodzi wa chinyamata mukupemphedwa kutenga mbali mu kafukufuku. Koma musanatenge mbali mukafukufuku ameneyu ndipofunika kuti munvetse. Kafukufuku ameneyu siwokakamiza ayi muli ndi ufulu osankha kutengapo mbali kapena ayi.

Kufunika kwakafukufu ameneyu

Kafukufukuyu ndi ofunika kwambiri chifukwa akhonza kudzapeza zilakolako za achinyamata pa nkhani ya ubereki. Zotsatira zakafukufuku ameneyu zikhonza kudzaunikila nkhani yakugonana ndizinthu zomwe zimachititsa achinyamata kusatsatira njira zolera kapena kusatsatira njira zolerazi. Zotsatira zakafukufuku zikhonza kudzaunikira ndondomeko zoyenera kuti mavuto amene achinyamata amakumana nawo kuti asalereachepe ndikupititsa patsogolo zinthu zomwe zimathandiza kuti achinyamata alere. Mwanjira ina, zotsatira zimenezi zikhonza kudzathandiza kupeza njira zomwe achinyamata angathandidzwire kuti akhale ndimwayi wochita chisankho pa moyo wawo waubereki, ndichoti azilera koteri izi zikonza kuzathandizanso kupititsa pasogolo moyo wawo waubereki.

Amene angatenge mbali pakafukufuku ameneyu ndindani?

Achinyamatha akazi okwana fifitini amene ali ndi zaka zobadwa 18 kufikila 19, komantso amene analengedza ndikuvomeleza kuti ali ndi HIV, ali ndi ufulu kutenga nawo mbali pakafukufuku ameneyu.

Kodi ine ndikhoza kutenga mbali mukafukufuku ameneyu?

Muli ndiufulu kutenga mbali pakafukufuku ameneyu kapena ayi. Ngakhale mutasankha kutenga mbali mulindiufulu kusiya kutenga nawo mbali ngakhale mutayamba kale popanda kupereka chifukwa chilichonse. Inuyo mutasankha kuti musatenge nawo mbali mukafukufukuameneyu palibe chilichonse chingakuchitikileni pankani ya chitandizo ku chipatala popeza ndi ufulu wanu kusankha chochita.

Chidzachitike ndi chiyani pochita kafukufukuyi?

Inu monga mmodzi otenga nawo mbali mu kafukufukuyu, mudzakumana ndi amene akupangitsa kafukufukuyu pamalo otsaonekela. Wopangitsa kafukufukuyu adza kujambulani mau ndi kulemba zina papepala. Zonsenzi zidzachitika pokapokha inu mutavomeredza. Inu ndinu omasuka kuwauza ochititsa kafukufukuwa kusiya kujambula ngati simukutsangalatsidwa ndidzimene akukambazo. Nthawi ina iliyonse mukhale omasuka kutuluka mukafukufuku ngati zomwe zikukambilwazo simukugwirizana nazo. Ngati mutatsintha maganizo anu, ndipo mukufuna kutuluka mukafukufukuyu, opangitsa kafukufukuyu adzakufunsani ngati angathe kugwiritsa ntchito zomwe ajambula kalezo. Mudzafunsidwa kuyankulapo pankani yaubereki, ndikufotokodza nkhani ygonana, ndi nkhani yakagwilitidwe ka njila solela. Kafukufuku ameneyu aza tengi mphindi sikisite kapena nayinte Atatha kukujambulani, opangitsa kafukufukuwa adzazitanthaudzira zojambula mu mau polemba papepala. Ndinu omasuka kuwerenga ndikuwonjezela ngati

mukufuna, komanso kufafanitsa zomwe sizinakusangalatseni. Cho jambulila mau tiza chisunga mukabati ndikukiya tikamalidza zose zakafukufuku.

### Kusunga chinsisi

Kutenga nawo mbali mu kafukufukuyu kutha kupangitsa kuti kukusungirani chinsinsi kwanu kutaike chifukwa anthu ena adzaona zotsatira za kafukufukuyu. Monga amene akupangitsa kafukufukuyu, mphuzinsi wamkulu ndi omuthandiza amene adzaone zotsatirazo. Iwowa adzayesetsa kukusungirani chinsinsi posaulula kuti munatenga nawo mbali mukafukufukuyu. Zotsatira zakafukufuku ameneyu zidzagwiritsidwa ntchito pophunzitsira, kupangira akafukufuku ena, kulengezetsa m'mapepala a za sayansi, komanso kumisonkhano yokambirana za sayansi. Ngati patafunika kuti.tifotokozere za zimene inu mwatiuza muli mukutsimikizidwa kuti sitidzagwiritsa ntchito dzina lanu, koma nambala yachinsinsi ija.

Kodi ndifunika kuwononga kapena kupeza ndalamu potenga nawo mbali mu kafukufukuyu?

Simukusowa kuperekwa ndalamu kuti mutenge mbali mu kafukufukuyu. Komanso simulipidwa chifukwa chotenga mbali mu kafukufukuyu ameneyu. Koma ngati mwagwiritsa ntchito ndalamu zanu kuyendere pobwera ku kafukufukuyu, ndalamu zimenezo tikubwezerani.

Pali cholowa chimene chingakhalepo potenga mbali pakafukufukuyu?

Palibe cholowa chilichonse chimene mudzapeza chifukwa chotenga mbali mukafukufukuyu. Kungoti, mukatenga nawo mbali mukafukufukuyu, zidzathandiza achipatala kuthesa zilakolako za achinyamata amene ana badwa ndi HIV pa nkhani ya

ubereki. Zotsatira za kafukufukuyu ameneyu zidzawathandiza omwe amakonza ndondomeko za ubereki wa achinyamata kukonza njira zoyenera kuthandiza kuti azilera kapena momwe angayendetsele nkani ya ubereki.

Kodi ndi zovuta ziti zomwe zingakhalepo?

Kutenga mbali kwanu mukafukufukuyu kungakupangitsen kukhala ndi timavuto pang'ono. Timavutoti ndi monga; kukutayirani nthawi yanu pang'ono poyankha mafunso, komanso mafunso ena akhoza kukhala okupangitsani kusowa mtendere. Ngati mutaona kuti mukusowa mtendere ndimafunso ena, khalani omasuka kusawayankha mafunsowo, kapena kutuluka mukafukufukuyu.

Mukafuna kuziba zambili

Ngati muli ndi mafunso kapena mwakumana ndi zovuta zili zonse zokhuzana ndi kafukufukuyu mukhoza kuyimba foni kwa a Beatrice Mkandawire panambala yi: 0999 918 029. mukhonzanso kuyimbira foni kwa a kalembela wa kafukufuku ku College of Medicine pa nambala yi.**01871911**

## **APPENDIX C: CONSENT FORM**

**PLEASE READ AND SIGN THIS FORM IF YOU ARE TAKING PART IN THIS  
STUDY**

I have been fully informed on the attached information sheet about the study

I understand that participation is free and I am free to withdraw any time without giving reasons and this will not affect the care rendered to me in the clinical area.

I know that the information that I will give to the researcher should not be used against me in future.

I understand that my information will be kept confidentially and will only be accessed by the researcher or those people directly concerned with this study.

I understand that I will not benefit financially

I know how to contact the researcher if need be

I agree to voluntarily participate in the study, be questioned and provide answers to the best of my knowledge

I give my permission to audio tape the interviews.

---

Participant's Name

---

Signature

---

Date

---

Name of person taking consent

---

Signature

---

Date

(if different from researcher)

----- ----- -----

Researcher's Name

Signature

Date

For any queries and clarification contact; The Secretariat, College of Medicine  
Research Committee, Private Bag 360, Chichiri, Blantyre 3 or call 01871911

**THANK YOU FOR TAKING PART IN THIS STUDY**

## **APPENDIX D: CHILOLEZO (CHICHEWA VERSION OF CONSENT FORM)**

Ndawerenga zomwe zalembedwa mukalatayi, komanso andifotokozerwa  
ndondomeko yonse ya kafukufukuyu.

Ndamva kuti zonse zomwe ndidzafotokoze mukafukufukuyu zizatetedzedwa  
posungidwa mwachinsinsi ndipo sizidzagwirisidwa ntchito motsutsana nane.

Ndanvetsetsa kuti palibe cholowa chomwe ndingachipeze potenga mbali  
mukafukufukuyu ku nkhanzi ya ndalamu.

Ndanvetsa kuti ndili ndi ufulu osiya kutenga nayo mbali mukafukufukuyu nthawi  
iliyonse popanda kupereka chifukwa chilichose

Ndapatsidwa mwayi ofunsa mafunso ndipo mafunso anga anayankhidwa, komanso  
ndapatsidwa maina ndima nambala amafoni a anthu amene ndingathe kuwafunsa ngati ndili  
ndi mafunso ena.

Ine ndikuvomeledza kutenga nawo mbali mukafukufuku ndipo ndilandira kalata  
yosonyeza kulola kwanga ndikatha kusayina kalata ya chilolezoyi.

Ine ndikupereka chilolezo changa kuti akhonza kundijambula mau pamene  
akundifunsa mafunso.

Dzina la otenga mbali

Saini yake

Tsiku

Dzina la opangitsa kafukufuku

Saini yake

Tsiku

(Kapena omuthandizira) .....

.....

.....

Ngati muli ndi mafunso kapena dandaulo lemerani kalata kwa: a kalembela,  
College of Medicine Research Committee (COMREC), Private Bag 360, Chichiri, Blantyre  
3. Kapena imbani foni pa 01 871 911.

**ZIKOMO POTENGA NAWO MBALI PA KAFUKUFUKU**

## **APPENDIX E: INTERVIEW GUIDE**

Code Number -----

Date of interview -----

Age -----

Marital status -----

Number of Children -----

Religion -----

Education -----

Born with HIV -----

### **REPRODUCTIVE NEEDS**

What knowledge do you have on the reproductive health services available?

What revisions in reproductive health services would you desire (*Probe reasons for this response*)

What reproductive health services would you desire added to the existing services that you receive? (*Probe why the mentioned services*)

What are your pregnancy aspirations? (*Probe on reasons*)

How would you react to a pregnancy now? (*Probe on reasons*)

What are your intentions with regards marriage? (*Probe on reasons*)

### CONTRACEPTIVE KNOWLEDGE

What type of information have you received so far regarding contraceptives? (*Probe on adequacy of the information*)

In what circumstances did you receive information on contraceptives?

What type/types of contraceptives do you know?

What other contraceptive options available that health service providers have told you that you can use?

### CONTRACEPTIVE ACCESS

Where do you think you can find contraceptives? (*Probe reasons for this response*)

Where would you prefer to access FP services? (*Probe reasons for this response*)

What difficulties do you encounter when accessing FP services?

### CONTRACEPTIVE USE

Which FP method would you prefer to use? (*Probe reasons on those chosen*)

What type/types of contraceptive method do you use? (*Probe reasons for this response*)

What encourages you to use contraceptives? (*Probe reasons for this response*)

## SEXUAL PRACTICES

What is your experience with dating? (Probe on reasons)

How is your sex life? (Probe on reasons)

When was your first sexual encounter? (Probe: at what age?)

How many sexual partners have you had during this year? (Probe: frequency).

## **APPENDIX F: MLOZERA WA MAFUNSO**

Nambala yachinsinsi.....

Tsiku lokambirana.....

Zaka .....

Pabanja.....

Nambala ya ana.....

Chipembezo.....

Mapunzilo.....

Munabadwa ndi HIV .....

### **ZOKUMBA ZA UBELEKI**

Chonde difotokodzeleni, mukudziwapo chani pa chitandizo cha ubeleki chomwe chilipo?

Ndi chitandizo chiti mungafune chita chosedwa pa kani ya kulela? (*fufuzani zifukwa*)

Ndi njila ziti zina zakulela zomwe zilipo zimene a chipatala ana ku fotokozelani kuti mutha kugwilitsa nchito?

Kodi malingalilo wo tenga mimba ndiotani (*fufuzani zifukwa*)

Kodi mutakala ndi mimba panopa mungatani? (*fufuzani zifukwa*)

Kodi malingalilo wozakhala pa banja ndi otani? (*fufuzani zifukwa*)

## KUTHEKERA KO DZIWA NJIRA ZOLERA?

Munauzidwa chani za njira zakulera? (fufuzani kuchuluka kwa nfundo)

Kodi munauzidwa munjira yanji? Kapena kuti chinachitika ndichiyani kuti muuzidwe zanjira zakulera?.

Chonde difotokozeleni njila zakulela zomwe mukudziwa

Ndichithandizo chiti kapena ziti zowonjezela pankhani ya ubereki zomwe mungafune pambali pa zomwe mukulandila dzii? (*fufuzani zifukwa*)

## KUPEZA NJIRA ZOLERA?

Kodi njira zolera munga zipeze kuti?

Kodi inuyo munga konde kupeza njila zolela kuti? (*fufuzani zifukwa*)

Ndimavuto ati mumakumana nawo pogwiritsira ntchito njira zolerazi

## KUGWIRITSA NTCHITO NJIRA ZOLERA

Ndifotokozeleni njila zolela mungakonde kugwilitsa ntchito (*fufuzani zifukwa*)

Ndifotokozeleni njila zolela zomwe mumagwiritsa ntchito? (*fufuzani zifukwa*)

Kodi chimene chimakulimbikitsa ku gwiritsa ntchito njira zolera ndi chiyani? (*fufuzani zifukwa*)

## MUCHITIDWE WO GONANA

Choyamba ndifotokozeleni za umoyo wanu wa chikondi (*fufuzani zifukwa*)

Kodi umoyo wanu wo gonana ndi amuna ndiwotani? (fufuzani zifukwa)

Munagonana liti koyamba ndi mwamuna? (fufuzani: Mulindizaka zingati?)

Mwagonana ndi amuna angati muchaka chino? (Fufuzani: kangati)

## **APPENDIX G: A LETTER TO COMREC**

Kamuzu College of Nursing,  
P.O.BOX 415  
Blantyre.  
20<sup>th</sup> May, 2014

The Secretariat  
College of Medicine Research Ethics Committee (COMREC)  
P.O. P/B 360  
Chichiri  
Blantyre, 3

Dear Sir,

**RE: REQUEST TO CONDUCT RESEARCH ON “REPRODUCTIVE HEALTH NEEDS AND SEXUAL PRACTICES OF ADOLESCENT WITH PERINATALLY ACQUIRED HIV”**

I am Beatrice Mkandawire, a student at Kamuzu College of Nursing pursuing a Master’s Degree in Child Health Nursing. I would like to seek permission to conduct a study on the mentioned topic at Baylor (Lilongwe). This is in partial fulfillment of the program for the award of a Master Degree.

The study seeks to identify reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV, specifically determining their pregnancy and marriage aspiration, contraceptive knowledge access and use, while identifying gaps between these needs and existing health services. The results of the study shall provide

information which will help in identifying measures to promote reproductive health services which are tailor made to suit their needs.

I will endeavor to abide by the ethical rules and regulations as laid down by the ethics committee. On completion of the study, a copy of the report findings will be submitted to your office.

Data will be collected by means of in-depth interviews. The selection of participants will be done through purposive sampling. Initially 15 female participants, aged between 18-19 years will be recruited but the exact number will be decided by data saturation. All measures will be taken to ensure participants confidentiality and anonymity. No names will be mentioned only numbers and the tapes will be destroyed after data transcription. There are no risks involved in this study, however in case of emotions; the researcher will counsel the participants when stressed as a result of their participation in the study.

Your permission will be greatly appreciated.

Yours faithfully,

Beatrice Mkandawire (Mrs).

## APPENDIX H: COMREC CERTIFICATE

<b>C E R T I F I C A T E   O F   E T H I C S A P P R O V A L</b>	
	
This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:	
<b>P.071/14/1594 - Reproductive Health Needs and Sexual Practices of Adolescents with Perinatally Acquired HIV version 3 by Beatrice Mkandawire</b>	
On 08th January 2015	
<i>As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page</i>	
 Dr. V. Mwapaşa - Chairperson (COMREC)	Approved by College of Medicine
08/01/15 Date	08/01/15 Date
(COMREC) Research and Ethics Committee	

## **APPENDIX I: LETTER OF PERMISSION**

Kamuzu College of Nursing,  
P.O.BOX 415,  
Blantyre  
20<sup>th</sup> July, 2013

The Executive Director  
Baylor College of Medicine Children's Foundation – Malawi  
P/Bag B 397  
Lilongwe

Dear Sir,

**RE: REQUEST TO CONDUCT RESEARCH ON “REPRODUCTIVE HEALTH NEEDS  
AND SEXUAL PRACTICES OF ADOLESCENT S WITH PERINATALLY ACQUIRED  
HIV”**

I am Beatrice Mkandawire, a student at Kamuzu College of Nursing pursuing a Master’s Degree in Child Health Nursing. I would like to seek permission to conduct a study on the mentioned topic at your institution (Baylor Lilongwe). This is in partial fulfillment of the program for the award of a Master Degree.

The study seeks to identify reproductive health needs and sexual practices of female adolescents with perinatally acquired HIV, specifically determining their pregnancy and marriage aspirations, contraceptive knowledge, access and use, while identifying gaps between these needs and existing health services. The results of the study shall provide

information which will help in identifying measures to promote reproductive health services which are tailor made to suit their needs.

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Your permission will be greatly appreciated.

Yours faithfully,

Beatrice Mkandawire (Mrs).



# BIPAI

Baylor International  
Pediatric AIDS Initiative

Baylor College of Medicine  
Children's Foundation—Malawi  
Kamuzu Central Hospital  
Private Bag B-397  
Lilongwe 3, Malawi  
Phone: +265 (0)1 750 877/679/753 095/098  
Fax: +265 (0)1 751 873  
Email: administration@baylor-malawi.org

**Dr. P.N. Kazembe, Executive Director**  
Baylor College of Medicine – Abbott Fund Children’s Clinical Centre of Excellence  
**Board of Trustees**  
Prof. Mark W. Kline, M.D. Chairman  
Michael B. Mizwa, Vice-Chairman  
Nancy R. Calles, Secretary  
David C. Jones, Member

2<sup>nd</sup> August 2013

Dear Beatrice,

In reference to your request to have Baylor College of Medicine Children’s Foundation-Malawi be your research site for the fulfillment of your Masters Degree, please be informed that your request has been accepted.

You are hereby requested to adhere to the code of conduct of the institution while you are within the Institution’s premises.

We are looking forward to assisting you in your course work.

Yours sincerely,

Joseph Mhango

For Dr. P.N. Kazembe  
Executive Director.

**APPENDIX J: CERTIFICATE FOR PROTECTING HUMAN RESEARCH  
PARTICIPANTS**

**Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Beatrice Mkandawire** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 04/02/2015

Certification Number: 1733032